



Aged care, end-of-life and palliative care

Report No. 33, 56th Parliament
Health, Communities, Disability Services and
Domestic and Family Violence Prevention Committee
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Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee

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Abbreviations

ABS	Australian Bureau of Statistics
AASW	Australian Association of Social Workers
ACAP	Aged Care Assessment Program
ACAR	Aged Care Approvals Round
ACAT	Aged Care Assessment Team
ACFA	Aged Care Financing Authority
ACFI	Aged Care Funding Instrument
ACP	Advance Care Planning
ACP facilitators	Advance Care Planning facilitators
ACQSC	Aged Care Quality and Safety Commission
ACQSC Act	<i>Aged Care Quality and Safety Commission Act 2018 (Cth)</i>
ADA Australia	Aged and Disability Advocacy Australia
Aged Care Act	<i>Aged Care Act 1997 (Cth)</i>
AHD	Advance Health Directive
AHPRA	Australian Health Practitioner Regulation Agency
AIHW	Australian Institute of Health and Welfare
AMA	Australian Medical Association
ANZSGM	Australian & New Zealand Society for Geriatric Medicine
BPSD	Behavioural and psychological symptoms of dementia
CALD	Culturally and linguistically diverse
Carnell Paterson Review	Ms Kate Carnell AO & Professor Ron Paterson ONZM, <i>Review of National Aged Care Quality Regulatory Processes</i> , October 2017
CDC	Consumer Directed Care
CHSP	Commonwealth Home Support Programme
CN	Community nursing
the committee	Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee

CoS	Continuity of Support
COTA	Council of the Ageing
CPCRE	Centre for Palliative Care Research and Education
CVS	Community Visitor Scheme
DACS Fund	Dementia and Aged Care Services Fund
DBMAS	Dementia Behaviour Management Advisory Service
DVA	Department of Veterans' Affairs
ECCQ	Ethnic Communities Council of Queensland
EPoA	enduring power of attorney document
the Framework	Aged Care Diversity Framework
GP	general practitioner
Guarantee Scheme	Accommodation Payment Guarantee Scheme
HHS	Hospital and Health Service
the Inquiry	Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying
IRC	Industry Reference Committee
LASA	Leading Age Services Australia
LCAQD	Lutheran Church of Australia Queensland District
LGBTIQ+	lesbian, gay, bisexual, transgender, intersex and queer
LLLB	Living Longer Living Better
LSA	<i>Legislative Standards Act 1992</i>
MBS	Medicare Benefits Scheme
MPHS	Multi-purpose Health Service
NACAP	National Aged Care Advocacy Program
NDIS	National Disability Insurance Scheme
NP	Nurse Practitioner
Office of ACP	Office of Advance Care Planning

OHO	Office of the Health Ombudsman
OPAN	Older Persons Advocacy Network
PCC4U	Palliative Care Curriculum for Undergraduates
PCQ	Palliative Care Queensland
PEPA	Program of Experience in the Palliative Approach
PCW	personal care worker
PHN	Primary Health Network
POQA	<i>Parliament of Queensland Act 2001</i>
QAS	Queensland Ambulance Service
QLS	Queensland Law Society
QNMU	Queensland Nurses and Midwives' Union
QSPCSMDG	Queensland Specialist Palliative Care Services Medical Directors' Group
RACF	residential aged care facility
RAD	refundable accommodation deposit
RANZCP	The Royal Australian & New Zealand College of Psychiatrists, Queensland Branch
RAS	Regional Assessment Service
Roadmap	Aged Care Roadmap
Royal Commission	Royal Commission into Aged Care Quality and Safety
RUCS	Resource Utilisation and Classification Study
SBRT	Severe Behaviour Response Teams
SDCP	Specialist Dementia Care Program
SIRS	serious incident response scheme
SoC	statement of choices
STRC	Short-Term Restorative Care
SVHA	St Vincent's Health Australia
Tune Review	David Tune AO PSM, <i>Legislated Review of Aged Care 2017</i>
VET	Vocational education and training

VHC	Veterans' Health Care
WA	Western Australia

Glossary

End-of-life care	End-of-life care refers to healthcare services aimed at meeting the health needs of people (including infants and children) whose life expectancy is anticipated to be shortened as a result of known life-limiting conditions, and where the primary intent of care may have shifted from life prolongation to a focus on quality of life.
Frailty	A multidimensional geriatric syndrome characterised by a decline of physical and cognitive reserves that leads to increased vulnerability. Frailty increases with age and is associated with falls, longer stays in hospital, difficulty recovering from illness and surgery, and mortality.
Older people	Refers to non-indigenous people aged over 65 years and indigenous people over 50 years.
Multi-purpose Health Service	A Multi-purpose Health Services (MPHS) is generally established in rural areas where populations are not large enough to support a separate hospital, residential aged care and home/community care services.
Nurse practitioner	A nurse practitioner is a registered nurse whose registration is endorsed under the Health Practitioner National Law, section 95, as being qualified to practice as a nurse practitioner. This endorsement indicates the person has the additional education, training and competence required to assume additional roles, functions, responsibilities and decision-making activities.
Palliative care	Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
Primary health care	Primary health care is generally the first contact a person has with Australia's health system. It relates to the treatment of patients who are not admitted to hospital.
Primary Health Networks	PHNs provide the infrastructure to support, adjust and reform the primary health care system within their regions. They were specifically created to identify and address the gaps in primary health care. PHNs work collaboratively with other regional health stakeholders to plan, design and commission evidence-based health services that support the specific needs of local communities and better integrate the health system at the local level.
the Viewer	Queensland Health electronic hospital record is known as the Viewer.

Chair's foreword

In November 2018, the Legislative Assembly ordered the committee to undertake a major inquiry into the delivery of aged care, end-of-life care and palliative care, and community and health practitioners' views on voluntary assisted dying.

This report presents the committee's findings and recommendations covering aged care, end-of-life care and palliative care. The committee has resolved to report findings on voluntary assisted dying separately.

I thank all submitters and witnesses who provided their views on the delivery of aged care, end-of-life care and palliative care in Queensland. The committee particularly appreciates the deeply personal stories members of the public shared about their loved ones in residential aged care facilities, as well as those undergoing palliative and end-of-life care.

I also acknowledge the important work of the Royal Commission into Aged Care Quality and Safety. I thank Commissioners and senior staff for their willingness to work cooperatively with the committee and to share information in one of the most challenging areas of health care: our aged care sector.

Regrettably, I cannot say the same for the Commonwealth Department of Health or the Aged Care Quality and Safety Commission. They declined our requests for information and assistance and contributed little to the inquiry.

The current Coronavirus pandemic highlights the importance of ensuring our aged care sector is properly funded, resourced and regulated to enable the appropriate level of care to be provided. This should be regardless of whether an elderly person is a resident of an aged care facility or resides in their own home. Our older Australians deserve no less.

From what we have seen and heard in our work, the committee holds grave concerns for the welfare of our older Australians trying to access care at home or in residential aged care facilities. We heard on multiple occasions in our travels throughout the state of older Australians waiting so long for their approved home care package that they were forced to move into a residential aged care facility. Sadly many older Australians die while waiting for their home care packages. From the evidence provided to the committee, it seems the more help an older person needs, the longer they have to wait for that help.

Everyone who needs aged care should be able to access care without having to wait two or three years, and at the level of care they need, not a lower level of care. Sadly our aged care system seems more focused on economic efficiencies rather than meeting the needs of our elderly.

Operators of residential aged care facilities told of their struggle to provide appropriate care when funding has been frozen and doesn't accurately reflect the real costs of providing care. As a result of these funding issues, we heard about inadequate staffing, both in numbers and training, inadequate care and cost-cutting which is clearly affecting the health and well-being of residents.

We also noted the burden placed on our public health care system by residential aged care facilities that can't, for various reasons, provide the care their residents need. The committee heard of many hospital and health services having aged care residents in their acute care hospital beds for long periods of time, either waiting for a bed or waiting to return after being admitted for care that could have been provided in their nursing homes. There is a need to improve both the standards and levels of coordinated care in residential aged care facilities to overcome this burden on public hospitals.

We have a rapidly ageing population, with dementia being one of the biggest health challenges for aged care and health care providers. More must be done as soon as possible to meet the projected significant increase in demand for aged care services in Queensland.

In relation to palliative care and end-of-life care, I want to thank every health care professional, volunteer and family member who came forward to share their often deeply personal experiences. There is no doubt palliative care plays an important role in our health care system.

I particularly thank and acknowledge the outstanding level of care and compassion that is demonstrated by hospice staff, palliative care doctors, nurses and volunteers who provide spiritual and pastoral care to people receiving palliative care or who are at the end of their lives. I also acknowledge Palliative Care Queensland for the important work they do and for their contribution to this inquiry.

The committee heard of the difficulties Queenslanders can face accessing palliative care, particularly in rural, remote and Indigenous communities. We also heard that approximately 70 percent of people would prefer to stay in their home or community when diagnosed with a terminal illness, surrounded by loved ones. However, only 14 percent of people are able to remain in the home as it is too difficult to access high level home-based care in many parts of Queensland.

As a regional Member and former health care professional, I want to see improved access for regional Queenslanders who want to stay in their regional communities. More hospices should be available outside of South East Queensland, and I believe increased collaboration between primary health networks, community organisations, and our hospital and health services is crucial to improving access to hospice care in rural, remote and Indigenous communities.

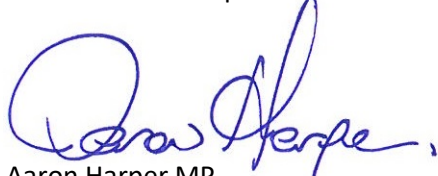
The inquiry's very broad terms of reference and the highly sensitive nature of the issues covered have made for a very difficult and heavy workload over the last 15 months. As Chair of the committee, I would like to recognise all committee members for their diligence and the genuine engagement, empathy, understanding and compassion they brought to the inquiry.

I would also like to thank and acknowledge other members who participated: Mr Jim McDonald MP, Member for Lockyer; Mr Sam O'Connor MP, Member for Bonney; and Ms Julieanne Gilbert MP, Member for Mackay, who substituted for committee members when they were unable to attend hearings. I also thank Mr Joe Kelly MP, Member for Greenslopes, for his considered submission, and other members who attended the committee's hearings: Mr Chris Whiting MP, Member for Bancroft; Mr Trevor Watts MP, Member for Toowoomba North; Mr Michael Healy MP, Member for Cairns; Mr Scott Stewart MP, Member for Townsville; Mr Ted Sorensen MP, Member for Hervey Bay; Mr Stephen Bennett MP, Member for Burnett; Mr David Batt MP, Member for Bundaberg; Ms Brittany Lauga MP, Member for Keppel; Ms Jen Howard MP, Member for Ipswich; Mrs Charis Mullen MP, Member for Jordan; Mr Ray Stevens MP, Member for Mermaid Beach; Mr John-Paul Langbroek MP, Member for Surfers Paradise; Ms Meaghan Scanlon MP, Member for Gaven; and Mr Linus Power MP, Member for Logan.

I am grateful for the support shown by members of the House for the inquiry who attended our proceedings. Their attendance highlights the importance of the issues covered by our inquiry in their communities.

I also acknowledge the work and support provided by the committee's secretariat and other staff within the Committee Office, the Parliamentary Reporters and the Parliamentary Library.

I commend this report to the House.



Aaron Harper MP
Chair

Recommendations

Recommendation 1 Trial of nurse practitioners 62

The committee recommends that the Australian Government allocate funding through the Primary Health Networks in Queensland to trial the use of nurse practitioners in residential aged care facilities. The trial could include expanding their scope of practice to prescribe certain medications and order certain pathology testing for residents in consultation with general practitioners.

Recommendation 2 Consistency of access to health services while in residential aged care 62

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Recommendation 3 Review of item numbers for visits by general practitioners to residential care 62

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Recommendation 7 Redesign of the My Aged Care website 76

The committee recommends that the Australian Government redesign the My Aged Care website to make it easier for all to use.

Recommendation 8 Information on aged care 77

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- The committee recommends that the Australian Government remove its cap on the number of packages available, at all levels, and provides as many packages as are needed.
- Recommendation 12 Clearing of backlog in Home Care Packages that have not provided 105**
- The committee recommends that the Australian Government clear the current backlog of packages that haven't been provided.
- Recommendation 13 Maximum waiting times for Home Care Packages 105**
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- The committee recommends that the Australian Government commit to provide interim care arrangements, close to the approved package level, for applicants for home care packages while waiting for their package to be provided.
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- Recommendation 16 Qualifications and training for personal carers providing in-home aged care 106**
- The committee recommends that the Australian Government consider whether there should be mandatory minimum qualifications and training for personal carers providing in-home aged care.
- Recommendation 17 Controls on physical and chemical restraints 167**
- The committee recommends that the Australian Government continues to examine and reform practices regarding physical and chemical restraints to discourage providers from using restraints as substitutes for appropriate levels of care and supervision.
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- Recommendation 19 Funding for activities to increase residents' social connectedness 167**
- The committee recommends that the Australian Government consider providing funding for activities to increase residents' social connectedness as well as physical and mental engagement in residential aged care facilities.
- Recommendation 20 Disclosure of staff to resident ratios at residential aged care facilities 167**
- The committee recommends that the Australian Government require providers to display in a public common area at each residential aged care facility the staff to resident ratios at that facility across each shift, for the information of residents, prospective residents and their representatives.

Recommendation 21 Publication of staff to resident ratios on the My Aged Care website 167

The committee recommends that the Australian Government require that information about residential aged care facilities that is published in the Schedule to the My Aged Care website includes staff to resident ratios at each of those facilities.

Recommendation 22 Advance Health Directives in residential aged care facilities 167

The committee recommends that the Australian Government require residential aged care facilities to provide information and encourage residents to complete an Advance Health Directive as soon as possible after entry to the facility. This information should be readily available for relevant health care workers.

Recommendation 23 Establishment of a funded aged care community visitor scheme 180

The committee recommends that the Australian Government consider establishing a funded aged care community visitor scheme to help address risks of elder abuse for older people receiving aged care.

Recommendation 24 Training and resources about special needs clients 200

The committee recommends that the Australian Government consider requiring aged care providers to ensure all aged care staff have access to training and resources to promote awareness and understanding of the special needs of clients who are from groups with special needs such as clients:

- suffering from mental health issues
- from culturally and linguistically diverse backgrounds
- from Aboriginal and Torres Strait Islander communities, and
- from LGBTIQ+ communities.

Recommendation 25 Training opportunities for Aboriginal and Torres Strait Islander people 200

The committee recommends that the Australian Government fund trainee positions for Aboriginal and Torres Strait Islander people to work in roles providing aged care and health care for Aboriginal and Torres Strait Islander people.

Recommendation 26 Mandatory dementia care training for all aged care workers 200

The committee recommends that the Australian Government mandate that accredited dementia care training is undertaken by all aged care workers.

Recommendation 27 Reducing the number of young people in aged care facilities 200

The committee recommends that the Australian Government act immediately to reduce the number of young people with health issues entering residential aged care facilities, and to provide them alternative housing arrangements that meet their requirements.

Recommendation 28 Expanded criteria for audits of residential aged care facilities 226

The committee recommends that the Australian Government require that the criteria covered by audits of residential aged care facilities be expanded to cover internal processes, resident safety, capacity to meet residents' needs and the standard of accommodation.

Recommendation 29 Graded scale for compliance with aged care standards 226

The committee recommends that the Australian Government require that the current system of pass/fail for compliance with standards be replaced with a graded system.

Recommendation 30 Separation of accreditation and compliance systems 226

The committee recommends that the Australian Government require that the accreditation system is separated from the regulatory system.

Recommendation 31 No prior notice of audits of facilities 226

The committee recommends that the Australian Government cease the practice of providing prior notice to providers of compliance audits of residential aged care facilities.

Recommendation 32 Ground truthing of audit findings by residents 226

The committee recommends that the Australian Government require that, as part of the audit process, residents and their representatives are provided with the opportunity to contribute to the audit process and audit findings are shared with residents and their representatives for comment before finalising the audits.

Recommendation 33 Publication of compliance monitoring reports 227

The committee recommends that the Australian Government require the Aged Care Quality and Safety Commission to publish all compliance monitoring update reports.

Recommendation 34 Publication of accreditation reports after a change of provider 227

The committee recommends that the Australian Government require the Aged Care Quality and Safety Commission to explain the commission's practices in relation to the removal from publication of accreditation reports of facilities after any change of approved provider occurs.

Recommendation 35 More accessible complaints system 227

The committee recommends that the Australian Government require that the Aged Care Quality and Safety Commission's complaints system for aged care be made more accessible and responsive to complaints.

Recommendation 36 Process for medical practitioners to report problems

The committee recommends that the Australian Government require that the Aged Care Quality and Safety Commission's complaints system promote mechanisms to encourage medical practitioners and allied health professionals to report problems they observe with the potential to compromise the safety and welfare of residents and other clients, on a confidential basis if necessary.

Recommendation 37 Disclosure of staff qualifications and experience 227

The committee recommends that the Australian Government require that providers of residential aged care services disclose to residents, prospective residents and their representatives the qualifications, training and experience of their staff at the facility.

Recommendation 38 Audit of accredited aged care training courses 246

The committee recommends that the Australian Government ensure accredited training courses for aged care are producing graduates with the required skills and competencies to perform the tasks required of them.

Recommendation 39 Aged care staff training and development 246

The committee recommends that the Australian Government call on providers to promote a culture in the aged care industry of ongoing staff training and development.

Recommendation 40 Certificate 3 qualifications for personal carers 246

The committee recommends that the Australian Government consider requiring that training equivalent to Certificate 3 in aged care is mandatory for all personal care workers in the aged care sector. For existing employees with certificate 2 qualifications, there should be recognition of experience on the job in lieu of undertaking additional training.

Recommendation 41 Better pay and conditions for aged care workers 246

The committee recommends that the Australian Government raise the minimum pay and conditions of employment for personal carers, nurses, administrators and other workers in the aged care industry to levels equivalent to their peers in the health sectors.

Recommendation 42 Workforce strategy for aged care 246

The committee recommends that the Queensland Government, in conjunction with the Australian Government, unions representing aged care workers, peak bodies representing the aged care providers and training providers devise a strategy to recruit and train workers for Queensland's aged care providers to meet future staffing requirements, to meet the increasing aging population, and demand for services in Queensland.

Recommendation 43 National strategy implementation plan and monitoring and evaluation plan 318

The committee recommends that the Australian Government finalise and publish the Implementation Plan and the Monitoring and Evaluation Plan for the *National Palliative Care Strategy 2018* as soon as possible.

Recommendation 44 Revision of the 2015 End-of Life-Strategy 318

The committee recommends that the Queensland Government revise and update the *Statewide Strategy for End-of-Life Care 2015* in conjunction with the Australian Government, Primary Health Networks, Palliative Care Queensland and other peak bodies, consistent with the Clinical Services Capability Framework, to:

- specify what palliative care services and end-of-life care services are to be provided and in what form by government and non-government providers, including: specialist care services, telephone support, access to pharmacy services, grief and bereavement support, the delivery of awareness programs for health professionals and the general public, and interactions with aged care
- provide clear, meaningful targets for accessibility to, and the delivery and timeliness of, palliative care and end-of-life care services to all Queenslanders regardless of their location, including communities with special cultural and other needs, who are located in regional, rural and remote areas
- require that Queensland Health is responsible for coordinating and implementing the strategy across all Hospital and Health Services, and that department report annually on the performance by all Hospital and Health Services against the accessibility, delivery and timeliness targets for palliative care and end-of-life care services
- provide goals and actions related to the delivery of training and education for palliative care and end-of-life workers
- link to other strategies and plans for the recruitment and retention of staff, and
- acknowledge that a key principle of palliative and end-of-life care is person-centred care.

Recommendation 45 Person-centred care 319

The committee recommends that any changes to the delivery of and access to palliative care services in Queensland promote person-centred care.

Recommendation 46 Increased transparency and accountability for palliative care services 319

The committee recommends that the Queensland Government increase transparency and accountability of palliative care services, by mandating reporting of data and setting clear performance standards.

Recommendation 47 Assistance for people wishing to die at home 320

The committee recommends that the Queensland Government and Primary Health Networks explore ways to fund and provide further assistance to communities and families to enable people to die at home supported by end-of-life care through: expansion of community and in-home nursing services; expansion of community care programs; supporting community-based medical aids and equipment loan schemes; and increased resources for the Hospital in the Home program which provides high-level care in the home when patients require it.

Recommendation 48 Assistance for regional hospices 320

The committee recommends that the Queensland Government with assistance from Primary Health Networks examine ways to help establish viable hospices outside of South East Queensland.

Recommendation 49 Paediatric palliative care

The committee recommends that all levels of government explore opportunities to establish a paediatric palliative care hospice outside of South East Queensland.

Recommendation 50 After hours palliative care 320

The committee recommends that the Queensland Government explore options to improve after-hours access to palliative care services, to ensure all Queensland palliative care patients have access to after-hours palliative care regardless of whether they are at home or in a residential aged care facility, hospice or hospital.

Recommendation 51 Centralised 24/7 telehealth service 321

The committee recommends that priority funding be allocated to establish a centralised 24-hour, seven day telehealth service available to practitioners caring directly for palliative patients throughout Queensland, and to develop a statewide supportive information system to allow practitioners to access real-time patient information for rapid response and appropriate treatment recommendations.

Recommendation 52 Capacity building for telehealth services 321

The committee recommends further development and capacity building of telehealth or other digital services for patient consultations to enable people in regional, rural and remote areas to access health services not locally available.

Recommendation 53 Increased Australian Government funding for palliative care 341

The committee recommends that the Australian Government increase the amount available through subacute funding for the delivery of palliative care to address the unmet need for services.

Recommendation 54 Increased Queensland Government funding for palliative care 341

The committee recommends that the Queensland Government increase its funding for palliative care in Queensland.

Recommendation 55 Options to prevent palliative care funding being diverted 341

The committee recommends that the Queensland Government examine options to ensure that palliative care funding is not diverted to other subacute areas.

Recommendation 56 Palliative and end-of-life care for residential aged care residents 341

The committee recommends that the Australian Government properly fund palliative care and end-of-life care services provided to residents living in private homes or in residential aged care facilities so residents can access the clinical care, nursing and specialist palliative care services they require. This will involve providing greater flexibility in the home care package system and a redesign of the Aged Care Funding Instrument to incorporate funding for palliative and end-of-life care.

Recommendation 57 Clinical capability framework for palliative care 344

The committee recommends that the Queensland Government, as a matter of urgency, mandate the application of the Clinical Services Capability Framework for Public and Licensed Private Health Facilities for palliative care planning and delivery by all Hospital and Health Services as part of their funding agreement, and monitor Hospital and Health Service performance in meeting this framework with explicit use of performance metrics and reporting.

Recommendation 58 Funding for specialist palliative care 344

The committee recommends that the Queensland Government consider as part of any broader review whether to develop a needs-based funding model for specialist palliative care which includes packages of care instead of time-limited funding models.

Recommendation 59 Develop a palliative care workforce strategy

The committee recommends that the Queensland Government, in conjunction with the peak bodies and unions representing the palliative care workers, model current and future workforce needs and develop a palliative care workforce strategy that aligns with the national strategy and that it includes strategies for:

- increasing the number of palliative care specialists, nurse practitioners, and palliative care nurses via specialised palliative care training and education
- professional development training for all providers of palliative care within the medical, nursing and allied health professions
- educating health workers who may need to provide palliative care as part of their normal health care delivery, for example, general practitioners, nurses and residential aged care facility workers, so they have a basic understanding of palliative care
- recruiting and retaining palliative care staff, and
- addressing issues of fatigue and isolation amongst palliative care staff.

Recommendation 60 Develop specialist support services 362

The committee recommends that the Australian and Queensland governments develop specialist support services to assist general practitioners, nurses, allied health workers and the aged care workforce, including ways to integrate services to provide support to care workers, such as through mentoring.

Recommendation 61 Incorporate palliative care into tertiary education and training 362

The committee recommends that the Australian and Queensland governments work to identify strategies to incorporate palliative care training into tertiary courses for medical, nursing and allied health staff, including through Palliative Care Curriculum for Undergraduates (PCC4U), and aged care training providers.

Recommendation 62 Mandatory basic training for personal care workers 362

The committee recommends that basic palliative care training be made mandatory for personal care workers in residential aged care facilities.

Recommendation 63 Continue funding for professional development programs 362

The committee recommends that the Australian and Queensland governments continue financial and other support for professional development programs, such as Program of Experience in the Palliative Approach (PEPA) and Centre for Palliative Care Research and Education (CPCRE).

Recommendation 64 Nurses in palliative care 362

The committee recommends that the Queensland Government explore opportunities to better utilise nurses, nurse navigators and nurse practitioners in the Queensland palliative care system to assist and provide palliative and end-of-life care.

Recommendation 65 Respite care for informal carers 369

The committee recommends that the Australian Government improve the availability of respite services for informal carers providing end-of-life care to the dying, and provide for more flexible delivery to allow for short-term respite.

Recommendation 66 Palliative care community education strategy 380

The committee recommends that the Queensland Government work with relevant stakeholders to develop a community awareness campaign to promote palliative care and increase knowledge of services available to patients and carers.

Recommendation 67 Community understanding of death, dying and options for end-of-life care 380

The committee recommends that the Queensland Government support Palliative Care Queensland and other stakeholders to increase the community's understanding of death, dying and options for end-of-life care.

Recommendation 68 Support for community initiatives 380

The committee recommends that the Queensland Government consider supporting the community initiatives recommended by Palliative Care Queensland in their submission.

Recommendation 69 Implement public education campaigns 394

The committee recommends that the Queensland Government work with relevant stakeholders to roll out a public education campaign to promote awareness of Advance Care Planning and its benefits amongst the community and within the health service to encourage people to discuss their preferences and choices for end-of-life care with health professionals.

Recommendation 70 Simplify Advance Care Planning documents 395

The committee recommends that Queensland Health continue to work with the Department of Justice and Attorney-General to ensure that Advance Care Planning documents are simple and accessible for users and health professionals.

Recommendation 71 Amend the *Guardianship and Administration Act 2000* 395

The committee recommends that the Queensland Government consider amending the *Guardianship and Administration Act 2000* to ensure that directives made at common law are legally binding.

Recommendation 72 Improve clinician access to Advance Care Plans 395

The committee recommends that the Queensland Government continue to roll out its system for registering advance care documents on The Viewer to ensure they can be accessed when necessary by treating clinicians, especially in times of emergency.

Recommendation 73 Promote clinician use of The Viewer 395

The committee recommends that the Queensland Government continue to promote the use of The Viewer to health professionals, so that its benefits can be more fully realised.

Recommendation 74 Dedicated Medicare Benefits Schedule rebates for advance care planning 395

The committee recommends that the Australian Government introduce dedicated Medicare Benefits Schedule rebates for clinicians undertaking Advance Care Planning activities with their patients.

Recommendation 75 Simplify advance care planning guidelines for health professionals 395

The committee recommends that the Queensland Government amend and simplify existing Advance Care Planning guidelines for health professionals to ensure that they understand their responsibilities as they relate to Advance Care Planning and can effectively undertake these responsibilities.

Recommendation 76 Further consideration of Queensland Law Reform Commission Report 422

The committee recommends that the Queensland Government consider the recommendations made by the Queensland Law Reform Commission in their report: *A Review of Queensland's Guardianship Laws* including omission of section 36(2) from the *Powers of Attorney Act 1998* to ensure a patient's directions to withdraw life-sustaining treatment are followed in accordance with their Advance Health Directive.

Recommendation 77 Prescribing of opioids 422

The committee recommends that the Queensland Government undertake an education campaign for health professionals working in palliative and end-of-life care to ensure understanding of the appropriate use of opioids for palliative and end-of-life care medication.

Recommendations from the Earle Haven investigation

The committee takes this opportunity to restate the recommendations of its *Report No. 30: Investigation of the closure of the Earle Haven residential aged care facility at Nerang*, tabled on 28 November 2019. Further explanation of these recommendations can be found in the committee's report on the closure of the Earle Haven residential aged care facility.¹

The Queensland Government has responded to recommendations 1, 2 and 5 that relate to it.

Recommendation 1 Returning home

The committee recommends that all options be explored to allow the residents evacuated from the facility to return to their home.

Recommendation 2 Strengthen evacuation planning measures

The committee recommends that the state government explore options to strengthen evacuation planning measures for residential aged care facilities, in consultation with federal government agencies responsible for aged care, to ensure they adequately cover the evacuation of residents and staff from facilities due to the sudden loss of care services.

Recommendation 3 Business continuity measures in aged care

The committee calls on the federal government to immediately institute business continuity checks, including equivalent vetting processes in relation to sub-contractor relationships, to prevent any recurrence of the Earle Haven disaster in other residential aged care facilities.

Recommendation 4 Equal accountability of aged care sub-contractor

The committee calls on the federal government to make sub-contractors equally accountable alongside approved providers for meeting quality and safety standards in the aspects of care they are sub contracted to deliver.

Recommendation 5 Sharing of 'Red Flag' information

The committee calls on the federal government to better share 'red flag' information about operators of residential aged care facilities with state and territory governments and other regulatory bodies to prevent any recurrence of the Earle Haven disaster in other residential aged care facilities.

Recommendation 6 Improving aged care sector reporting

The committee calls on the federal government to improve transparency by implementing improvements in aged care sector reporting.

Recommendation 7 Increased penalties for non-compliance with quality and safety standards

The committee calls on the federal government to increase penalties for significant non-compliance with quality and safety standards and review the capacity and powers of the Aged Care Quality and Safety Commission to effectively undertake this role.

Recommendation 8 Aged care commissioner

The committee calls on the federal government to set up an independent Aged Care Commissioner to provide oversight of the aged care system in Australia.

¹ Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, 2019, *Report No 30: Investigation of the closure of the Earle Haven residential aged care facility at Nerang*, November.

Recommendation 9 Review and redesign of aged care funding model

The committee calls on the federal government to immediately review and redesign its aged care funding model to guarantee the ongoing financial viability of the aged care sector, ensuring the funding model reflects the actual cost of care and makes adequate provision for the increasingly complex care needs of aged care residents.

Recommendation 10 Wage parity for aged care sector employees

The committee calls on the federal government to ensure that a redesigned funding model includes an increase in wages for aged care employees with a long-term aim to achieve wage parity with other health care sectors.

Recommendation 11 Introduction of aged care staffing ratios and minimum care hours

The committee calls on the federal government to mandate the introduction of minimum nurse, care worker and support worker skill mix ratios and minimum average daily resident care hours in private aged care facilities.

Recommendation 12 Physical and chemical restraints

The committee recommends that the federal government urgently examine and reform practices regarding physical and chemical restraints, and mandate staffing levels that will avoid these practices being used as substitutes for appropriate level of care and supervision.

Part 1 – Aged Care

1 Introduction

1.1 This report

This report is one of three reports and a volume of additional information from the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee's (the committee's) Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying (the inquiry).

This report presents the committee's findings on aspects of the inquiry terms of reference that relate to aged care and end-of-life and palliative care and voluntary assisted dying. The other publications from this inquiry are:

- Report No. 30: *Investigation of the closure of the Earle Haven residential aged care facility at Nerang*, tabled on 28 November 2019
- *Volume of additional information* tabled with this report. This volume lists: the submitters to the inquiry; the briefing officers and witnesses who gave evidence at the committee's 41 briefings and hearings for the inquiry, and lists the documents tabled during the inquiry and information provided in response to the committee's questions taken on notice at briefings and hearings, and
- Report No. 34: *Voluntary assisted dying* which the committee will table following this report.

1.2 Role of the committee

The committee is a portfolio committee of the Legislative Assembly which commenced on 15 February 2018 under the *Parliament of Queensland Act 2001* (POQA) and the Standing Rules and Orders of the Legislative Assembly.²

The committee's primary areas of responsibility are:

- Health and Ambulance Services
- Communities, Women, Youth and Child Safety
- Domestic and Family Violence Prevention, and
- Disability Services and Seniors.

Section 92 of the POQA provides that, in addition to performing a general legislative scrutiny and parliamentary oversight role in relation to its primary areas of responsibility, a portfolio committee is responsible for dealing with any issue referred to it by the Legislative Assembly or under another Act.³

Section 93(2) of the POQA provides that a portfolio committee is to deal with an issue referred to it by the Assembly or under another Act, whether or not the issue is within its portfolio area.

1.3 Inquiry referral and process

On 14 November 2018, the Legislative Assembly referred an inquiry to the committee with the following terms of reference:

1. That the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee inquire into aged care, end-of-life and palliative care and report to the Legislative Assembly on:

² *Parliament of Queensland Act 2001*, section 88 and Standing Order 194.

³ *Parliament of Queensland Act 2001*, section 92(2).

- a. the delivery of aged care, end-of-life and palliative care in Queensland across the health and ageing service systems; and
 - b. Queensland community and relevant health practitioners' views on the desirability of supporting voluntary assisted dying, including provisions for it being legislated in Queensland and any necessary safeguards to protect vulnerable persons.
2. That in undertaking the inquiry, the committee should consider:
- a. in relation to aged care, the terms of reference and submissions made to the Australian Government's Royal Commission into the Quality and Safety of Aged Care and, in recognising the Commission will occur in parallel, how to proactively work with the Commission to ensure an appropriate exchange of information to inform the conduct of the inquiry;
 - b. outcomes of recent reviews and work including Queensland Health's Palliative Care Services Review; and
 - c. the current legal framework, relevant reports and materials in other Australian states and territories and overseas jurisdictions, including the Victorian Government's Inquiry into end-of-life choices, Voluntary Assisted Dying Act 2017 (Vic) and implementation of the associated reforms.
3. That the committee report to the Legislative Assembly by 30 November 2019.⁴

On 17 July 2019, the committee resolved to undertake an investigation into the sudden closure of the Earle Haven residential aged care facility at Nerang. This investigation was undertaken as part of the inquiry, but with a separate submissions process and hearings. The committee made twelve recommendations from that investigation for the Federal Government and the Queensland Government to implement. Further details can be found in the committee's Report No. 30, 56th Parliament: *Investigation of the closure of the Earle Haven residential aged care facility at Nerang (Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying)*.⁵

On 22 August 2019, the Legislative Assembly agreed to a motion that the date for the inquiry into aged care, end-of-life and palliative care and voluntary assisted dying, be extended from 30 November 2019 to 31 March 2020.

1.4 Public awareness campaign

The committee undertook a range of activities to raise awareness of the inquiry and to assist groups and individuals contribute their views.

On 14 February 2019, the committee published an issues paper for the inquiry outlining the issues it would consider and the process for providing a submission.⁶

Copies of the issues paper were distributed to Queensland public and private hospitals, residential aged care facilities, Members of Parliament and other stakeholders for aged care, health, communities, law and government.

⁴ Legislative Assembly, 2018, *Record of Proceedings*, 14 November, p 3477.

⁵ Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, 2019, *Report No 30: Investigation of the closure of the Earle Haven residential aged care facility at Nerang*, November.

⁶ Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, 2019, *Paper No. 3, 56th Parliament, February 2019—Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying*.

The committee also provided information about the inquiry to over 4,000 groups and individuals registered to receive regular email updates about the committee's work.

The committee advertised the inquiry and call for submissions in major newspapers in February 2019. The committee placed further advertising to raise awareness of each of the public hearings and forums for the inquiry.

The details of the committee advertising and other work to raise awareness of the inquiry are included in the volume of additional information tabled with this report.

1.5 Submissions

The committee announced the call for submission on 14 February 2019 with a closing date of 15 April 2019. The committee continued to accept late submissions after the closing date.

In total, the committee accepted 4,719 written submissions for the inquiry. A list of submitters can be found in the volume of additional information tabled with this report and on the committee's website.

1.6 Briefings and hearings

The committee conducted 34 public and private hearings and briefings for the inquiry, and heard evidence from 502 invited witnesses. These included public hearings across regional centres along the east coast of Queensland as well as Mount Isa, Longreach, Mossman and Palm Island.

The committee held an additional seven hearings and briefings for the Earle Haven investigation, with 33 further witnesses appearing.

A list of hearings, briefings and witnesses is provided in the volume of additional information tabled with this report.

Unfortunately, this list does not include public briefings provided by the Commonwealth Department of Health. Despite being invited on a number of occasions to appear before the committee, either in person or via teleconference, as well as being given a choice of dates with each invitation, all invitations were declined other than to provide a written brief at the beginning of the committee's Inquiry. While the committee understands that the Royal Commission into Aged Care Quality and Safety has consumed a significant portion of the department's time, it is disappointing that a few hours over the course of a year could not be spared to assist the committee with its inquiry into aged care and end-of-life and palliative care.

1.7 Inspections

The committee visited a cross section of residential aged care facilities, hospices and palliative care facilities during the inquiry. A list of these inspections is included in the volume of additional information for the inquiry.

2 Ageing in Queensland

This section looks at the ageing population in Queensland, including changes in demographics and the impact this will have on the aged and health care sectors.

2.1 Ageing population and life expectancy

Queensland's population is rapidly increasing. In December 2017, the population reached 4.9 million people which equals 20% of the total population of Australia. Queensland's 2020 population of 5.1 million is projected to increase to over 6.22 million by 2036, an increase of 20.6%. By 2041, the population is expected to increase to between 6.5 million and 7.9 million people, with continued growth expected to result in a population of between 7.8 million and 11.5 million persons by 2066.⁷ However, this 20 percent increase understates a much more significant increase that will occur in older Queenslanders.

The age structure of the Queensland population is expected to change significantly over this period. While population increases are anticipated across all age groups, increases are in both the number and proportion of people in older age groups will be particularly significant. Queenslanders aged 65 years and older accounted for 14.7% of the population in 2016—this is projected to increase to between 19.5% and 20.9% by 2036, and between 23.8% and 25.8% by 2066.⁸ These increases will be driven in part by the ageing of people born during the baby boom in the post–World War II years, along with continuing increases in life expectancy. With our life expectancy now the fifth highest in the OECD, Queenslanders and other Australians are on average now expected to live almost ten years longer than 50 years ago.⁹

The number of Queenslanders aged over 65 are projected to more than double in number from 631,000 in 2020 to 1.301 million by 2036, an increase of 106%. The 85-years and over cohort is also growing rapidly. In 2016, the proportion of the Queensland population aged 85 and over was 1.8%, with that age group projected to grow to between 2.0% and 2.1% by 2026, and between 5.2% and 5.9% of the Queensland population by 2066.¹⁰ In terms of numbers, the number of over 85 is projected to increase from 90,324 in 2020 to 200,569 by 2036, an increase of 122%.

By 2050, almost 8% of the population are projected to be receiving aged care.¹¹

2.2 Causes of death

The top five causes of death are relatively consistent across Australia. Coronary heart disease is the leading underlying cause of death, followed by dementia and Alzheimer's disease, and cerebrovascular disease (which includes stroke). Lung cancer and chronic obstructive pulmonary disease make up the top five leading underlying causes of death in Australia in 2016, for males and females of all ages

⁷ Queensland Government Statistician's Office 2019, Queensland Government Population Projections, 2018 edition (medium series); *Queensland Regional Database*, <https://www.qgso.qld.gov.au/statistics/theme/population/population-projections/regions>.

⁸ Queensland Government Statistician's Office 2019, Queensland Government Population Projections, 2018 edition (medium series); *Queensland Regional Database*, <https://www.qgso.qld.gov.au/statistics/theme/population/population-projections/regions>.

⁹ Australian Government 2018, *Budget 2018-19 Fact Sheet – More Choices for a Longer Life*, ; OECD (2012), *Health at a Glance*, p7, https://www.health.gov.au/sites/default/files/more-choices-for-a-longer-life-overview_0.pdf.

¹⁰ Queensland Government Statistician's Office 2019, Queensland Government Population Projections, 2018 edition (medium series); *Queensland Regional Database*, <https://www.qgso.qld.gov.au/statistics/theme/population/population-projections/regions>.

¹¹ Productivity Commission, *Caring for Older Australians*, Report No. 53, 2011, Vol 1, p 2, <https://www.pc.gov.au/inquiries/completed/aged-care/report>.

combined.¹² In Australia between 2014 and 2016, there were over 380,000 deaths of people aged 65 and over (82% of all deaths). Only one in five (19%) of these deaths were of people aged 65–74, with 32% aged 75–84, 41% aged 85–94 and 8% for people aged 95 and over.¹³

Coronary heart disease was also the leading cause of death in each age group, except for those aged 65–74, whose leading cause of death was lung cancer. Dementia and Alzheimer’s disease featured as the second leading cause of death among people aged 75 and older.¹⁴

2.2.1 Causes of death in Queensland

The most recent figures on the primary causes of death report that in 2018 a total of 30,860 persons died in Queensland. This was comprised of 16,568 males (53.7%) and 14,292 females (46.3%).¹⁵ The most common leading underlying causes of these deaths listed in the order of their rates of morbidity, are shown in Table 1.

Table 1: Causes of Death, Queensland, 2018

Cause of death as classified by ICD-10 code ¹⁶	Total deaths		
	Males	Females	Persons
Total deaths	16,568	14,292	30,860
Neoplasms (Cancers - predominantly of digestive organs, of respiratory and intrathoracic organs, of bronchus and lung, genital organs, of lymphoid, haematopoietic and related tissue, breast, Melanoma, urinary tract)	5,555	4,092	9,647 (31.3%)
Diseases of the circulatory system (predominantly Ischaemic heart diseases and Cerebrovascular diseases)	4,082	4,025	8,107 (26.3%)
Diseases of the respiratory system (predominantly chronic obstructive pulmonary disease, influenza and pneumonia)	1,482	1,313	2,795 (9.1%)
External causes of morbidity and mortality (predominantly intentional self-harm, accidents, transport accidents, falls)	1,530	716	2,246 (7.3%)
Mental and behavioural disorders (predominantly dementia)	775	1,225	2,000 (6.5%)
Diseases of the nervous system (predominantly Alzheimer disease and Parkinson disease)	798	841	1,639 (5.3%)

Source: This table has been prepared by the committee using data from Australian Bureau of Statistics, *Causes of Death, Queensland, 2018* (Cat. No. 3303.0), Table 4.1

¹² Australian Institute of Health and Welfare, *Deaths in Australia, 2019*, <https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/leading-causes-of-death>

¹³ Australian Institute of Health and Welfare, *Older Australia at a Glance, 2018*, <https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/health-functioning/causes-of-death>

¹⁴ Australian Institute of Health and Welfare, *Older Australia at a Glance, 2018*, <https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/health-functioning/causes-of-death>

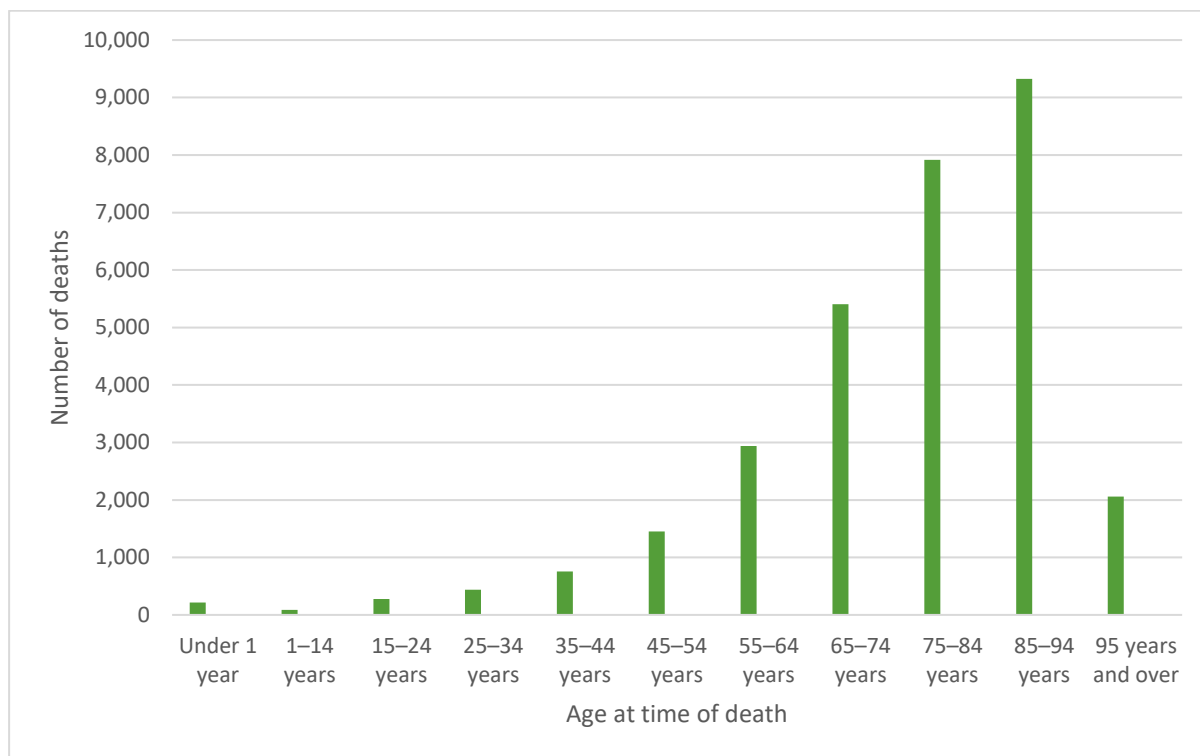
¹⁵ Australian Bureau of Statistics, *Causes of Death, Queensland, 2018* (Cat. No. 3303.0), <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/3303.0Main+Features12018?OpenDocument>

¹⁶ ICD-10 is the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD), a medical classification list by the World Health Organization (WHO). Please note that of the 20 ICD-10 Code categories, just the six categories with the highest number of deaths recorded in Queensland have been included in Table 1. The remaining 14 ICD-10 Code categories combined represented less than 15% of deaths in Queensland in 2018. The break-down of deaths by their ICD-10 Code as presented in Table 1 therefore does not add up to the total number of deaths.

2.2.2 Age at death in Queensland

When looking at the age of persons at their time of death, by far the highest proportion of deaths in Queensland (and Australia) occur in persons aged 65 years and above. To properly illustrate this, table 2 below shows the number of deaths by age group in Queensland in 2018.

Figure 1: Number of deaths by age group in Queensland



Source: This table has been prepared by the committee using data from Australian Bureau of Statistics, *Causes of Death, Queensland, 2018* (Cat. No. 3303.0), Table 4.3, (published September 2019).

2.3 Aboriginal and Torres Strait Islander Queenslanders

Queensland is home to a large proportion of Australia's Aboriginal and Torres Strait Islander peoples. In 2016, some 27.7 per cent of Australia's Aboriginal Torres Strait Islander population (798,365) lived in Queensland, making up 4.6 per cent of the total state population.¹⁷

Aboriginal and Torres Strait Islander people have a lower life expectancy in comparison to non-Indigenous Australians. The most recent figures report that in Queensland in 2017, life expectancy at birth was:

- 72 years for Indigenous males, 7.8 years lower than for non-Indigenous males (79.8 years)
- 76.4 years for Indigenous females, 6.8 years lower than for non-Indigenous females (83.2 years).¹⁸

¹⁷ Australian Bureau of Statistics, *Estimates of Aboriginal and Torres Strait Islander Australians, June 2016*, <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/3238.0.55.001Main+Features1June%202016?OpenDocument>, and Queensland Treasury, Queensland Government Statistician's Office, *Population, Aboriginal and Torres Strait Islander Queenslanders*, 30 June 2016, <https://www.qgso.qld.gov.au/issues/2791/population-aboriginal-torres-strait-islander-qlders-201606.pdf>

¹⁸ Department of Aboriginal and Torres Strait Islander Partnerships, *Queensland Closing the Gap Snapshot Report Card 2019*, p 3, <https://www.datsip.qld.gov.au/resources/datsima/programs/closing-gap/ctg-snapshot-2019.pdf>

Given this, the Aboriginal Torres Strait Islander population can access aged care support from the age of 50 compared to 65 years for other Queenslanders.¹⁹

The leading cause of death for Aboriginal and Torres Strait Islander people across Australia in 2017 was coronary heart disease, accounting for 11.5 per cent of all deaths. Diabetes was the second leading cause. Compared to 2016, the death rate from both coronary heart disease and diabetes in Aboriginal and Torres Strait Islander people has decreased (heart disease mortality decreased from 122.7 to 114.7 per 100,000 persons, and diabetes decreased from 88.2 per 100,000 to 83.3).

This reduction was consistent for both men and women (both causes showed a much larger decrease for males than females). The third leading cause for Aboriginal and Torres Strait Islander people in 2017 was chronic lower respiratory diseases.²⁰

2.4 Decentralisation

Queensland is a highly decentralised state, which has important implications for the delivery of aged care and end-of-life and palliative care services.

Approximately 40.4% of Queenslanders live outside major cities, with almost the same number (38.3%) living in regional areas. Of residents aged 65 or older, 473,350 (59.6 per cent) live in major cities, 195,706 (24.6 per cent) in inner regional areas, 108,633 (13.7 per cent) in outer regional areas, 10,156 (1.3 per cent) in remote areas and 6,417 (0.8 per cent) in very remote areas.²¹

Table 3 displays the total number of aged care service providers according to remoteness area in Queensland.

Table 2: Number of aged care service providers by remoteness area, Queensland, 30 June 2019

Remoteness area	Number of aged care service providers
Inner Regional Australia (Qld)	246
Major Cities of Australia (Qld)	629
Outer Regional Australia (Qld)	184
Remote Australia (Qld)	29
Very Remote Australia (Qld)	43
Total number of aged care service providers	1,131

Source: Compiled using data from the Australian Institute of Health and Welfare, *Aged Care Data Snapshot 2019* (fourth release).

¹⁹ Australian Government, *My Aged Care, Support for Aboriginal and Torres Strait Islander people*, <https://www.myagedcare.gov.au/support-aboriginal-and-torres-strait-islander-people>.

²⁰ Australian Bureau of Statistics, *Causes of Death, Australia, 2017*, (Cat. No. 3303.0), <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2017~Main%20Features~Leading%20causes%20of%20death%20in%20Aboriginal%20and%20Torres%20Strait%20Islander%20people~9>.

²¹ Australian Institute of Health and Welfare, *Aged Care Data Snapshot 2019* (fourth release), <https://www.gen-agedcaredata.gov.au/Resources/Access-data/2019/September/Aged-care-data-snapshot%E2%80%942019>.

2.5 The challenges of an ageing population

An ageing population presents social and economic challenges for individuals, communities and for governments in relation to systems of social and health care support.²²

2.5.1 Demand for aged care services

In particular, an increase in the number of older Queenslanders will mean a significant increase in both demand for, and spending on, aged care and health care services. According to the *2018-19 Report on the operation of the Aged Care Act 1997*, the ageing of the population and the associated increasing number of people with dementia are the two main factors driving increased demand for aged care services. However, the report notes that while older age groups have greater utilisation of aged care services, it is not age per se that determines access, rather, assessed need.²³

For females aged 65 years, the likelihood of entering residential care in their remaining lifetime is estimated at 54 per cent and for males aged 65 years, 37 per cent.²⁴

2.5.2 Demand for health services

Advances in health care have contributed to an increase in life expectancy. Conversely, an ageing population is also one factor contributing to the growing demand for health services, which has implications for the delivery of Queensland's health services.²⁵

The Australian Institute of Health and Welfare states the challenges of an ageing population for the health system are two-fold:

*...first, the rapidly growing group of 'old old' (85 and over) people who have a range of typical age-related health problems (for example, arthritis, dementia and cancer); and secondly, the younger cohort entering the '65 and over' age bracket with a larger burden of lifestyle-related diseases (for example, type 2 diabetes) than previous generations.*²⁶

Older people are also more likely than younger people to have multiple long-term health conditions.²⁷

According to Queensland Health, as people age they tend to use health services more often than younger people, and stay longer in hospital when they have an admission. The pressure this creates on the public health system is expected to increase as the population continues to age.²⁸

²² Australian Government, Productivity Commission, *Caring for Older Australians*, Report No. 53, 2011, Vol 1, p 2, <https://www.pc.gov.au/inquiries/completed/aged-care/report>

²³ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 6, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2018-19-ROACA.pdf

²⁴ Department of Health and Ageing, 2011, *Technical Paper on the Changing Dynamics of Residential Aged Care Prepared to Assist the Productivity Commission Inquiry Caring for Older Australians*, April, Canberra, <https://www.pc.gov.au/inquiries/completed/aged-care/residential-care-dynamics/residential-care-dynamics.pdf>

²⁵ Productivity Commission, *Caring for Older Australians*, Report No. 53, 2011, Vol 1, p 2, <https://www.pc.gov.au/inquiries/completed/aged-care/report>

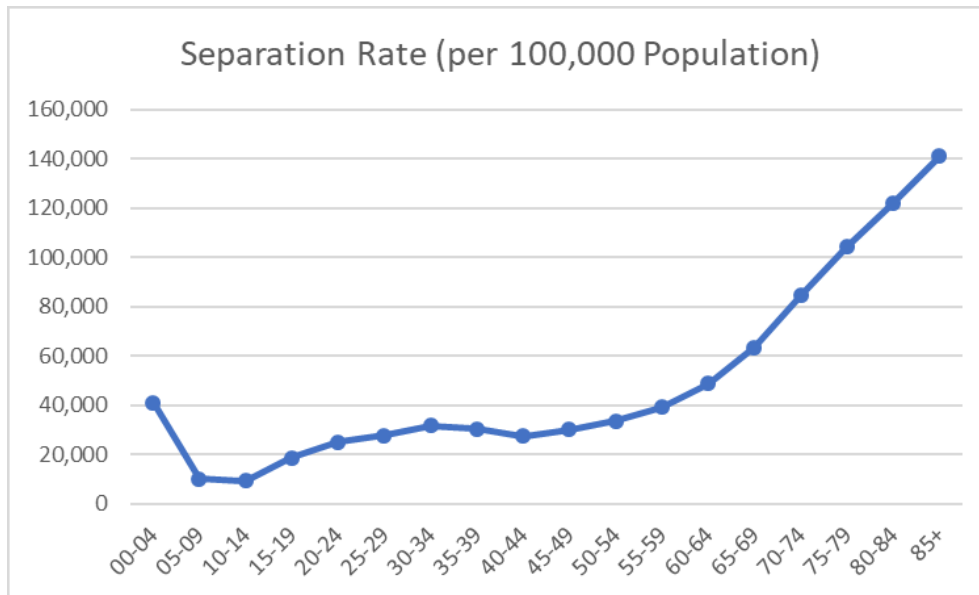
²⁶ Australian Institute of Health and Welfare 2014 *Australia's health 2014*. Australia's health series no. 14. Cat. no. AUS 178, p 2, https://www.aihw.gov.au/getmedia/19dbc591-b1ef-4485-80ce-029ff66d6930/6_9-health-ageing.pdf.aspx

²⁷ Australian Institute of Health and Welfare 2014 *Australia's health 2014*. Australia's health series no. 14. Cat. no. AUS 178, p 4, https://www.aihw.gov.au/getmedia/19dbc591-b1ef-4485-80ce-029ff66d6930/6_9-health-ageing.pdf.aspx

²⁸ Queensland Health, correspondence dated 23 January 2019, p 8.

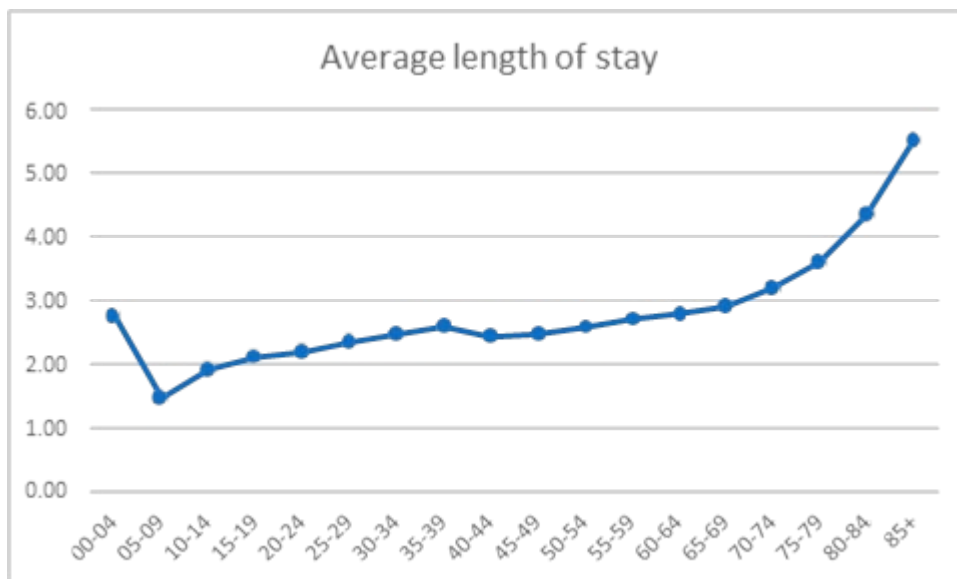
Queensland Health provided information demonstrating this relationship between age and hospital utilisation for public and private hospital admissions in Queensland during 2016/17 (see figures 1 and 2 below).²⁹

Figure 2: Relationship between age and hospital admission in Queensland 2016/17



Source: Correspondence from Queensland Health, dated 23 January 2019.

Figure 3: Relationship between age and length of hospital stay in Queensland 2016/17



Source: Correspondence from Queensland health, dated 23 January 2019.

According to Queensland Health, there are two main areas where the aged care system creates potentially avoidable pressure on the State's public health system:

- transfers from residential aged care facilities (RACFs) to acute health services (notably, hospital emergency departments), and

²⁹ Queensland Health, correspondence dated 23 January 2019, p 8.

- prolonged delays discharging medically fit older patients from hospital.³⁰

Despite an inability to identify RACF residents in hospital data, Queensland Health's health services research indicates that:

...compared with their community-dwelling peers, residential aged care facility residents have a higher rate of emergency department presentations and repeat visits, and are more prone to hospital acquired infections or complications. Emergency department utilisation by residential aged care facility residents is affected by access to general practitioners, availability of alternate residential aged care facility care and primary care, socio-demographic factors, and transportation facilities.³¹

Queensland Health also advised that patients staying in hospital longer than medically necessary is an ongoing issue in Queensland and across Australia, which has:

...wide-ranging negative impacts on the on the physical, social and emotional wellbeing of patients, as well as the efficiency and effectiveness of health services. This issue is particularly prevalent amongst the elderly who may be medically ready for discharge but are waiting for an Australian Government-funded home care package to return home or waiting for a suitable residential aged care place. These people are sometimes referred to as long stay older patients.³²

Queensland Health regularly undertakes a census of long stay older patients to monitor their prevalence, and to identify underlying causal factors and potential solutions. Results of the latest census from 2017 determined that a total of 9,761 occupied bed days were lost to long stay older patients who were considered safe for discharge from hospital if the appropriate community or residential aged care had been available. The main reason for delays in discharge are summarised in Table 4, with 'waiting for a residential care bed' being the leading reason.³³

Table 3: Reasons for delays in discharging long stay older patients

Reasons for delay in discharge (acute facilities only)	%
Waiting for residential care bed	71
Waiting for the family to make a decision	10.5
Difficult to place due to behaviour/dementia	6.5
Waiting QCAT hearing decision	5.5
Waiting on The Public Trustee to make a decision	1.5
Waiting for a private trustee to make a decision	1.5
Waiting on The Public Guardian to make a decision	1
Waiting on Centrelink Income and Assets test	1
Wait home care package	1
Difficult to place due to bariatric needs	-
Difficult to place due to complex care needs	0.5
Total	100

Source: Correspondence from Queensland health, dated 23 January 2019.

³⁰ Queensland Health, correspondence dated 23 January 2019, p 8.

³¹ Queensland Health, correspondence dated 23 January 2019, p 9.

³² Queensland Health, correspondence dated 23 January 2019, p 9.

³³ Queensland Health, correspondence dated 23 January 2019, p 9.

2.5.3 Older people with disabilities

Around one in every five Queenslanders (18.3 per cent) has a disability. For older age groups, the proportion with a disability is twice the average or higher: 36.6 per cent for 65-69 years; 47.6 per cent for 70-74 years; 50.9 per cent for 75-79 years; 63.5 per cent for 80-84 years; 74.1 per cent for 85-89 years; and 85.8 per cent for people aged 90 and over.³⁴

According to the AIHW:

*Compared to the general population, older Australians report higher levels of disabling conditions (or morbidities) such as dementia, paralysis, speech-related impairments, arthritis and hearing disorders. Many older Australians live with multiple disabling conditions (or co-morbidities) — people aged 65 or over reported an average of 2.8 health conditions in 2003.*³⁵

Difficulty in performing routine daily tasks like transport, health care, household chores, meal preparation and property maintenance are much more prevalent among older people. Physical frailty will often be a major obstacle to performing such daily tasks.³⁶

Hence, there is a large group of people with a disability who get their support through the aged care system. The AIHW states:

*While in the main, the clients of the aged care system are people who acquire a disability because of natural ageing, the system also currently funds and supports many older people who acquired a disability prior to the Age Pension age.*³⁷

As the population ages, and the incidence of people living with an age-related disability grows, this will have implications for the delivery of both the aged and health care sectors.

2.5.4 Increases in frailty, chronic disease and people living with dementia

An increase in life expectancy also means that more people experience increasing frailty and are living with chronic disease, and therefore require care and support.

Frailty is defined by the Frail Older Persons Collaborative as:

*...a state of increased vulnerability, associated with but distinct from increasing age and multi-morbidity, resulting in disproportionate adverse health outcomes following a stressor.*³⁸

Residents of RACFs typically represent the frailest population group in society, with chronic disease, atypical symptoms, multiple co-morbidities, cognitive and functional impairment, and social problems.³⁹

³⁴ Australian Bureau of Statistics 2016, *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*. Cat no 4430, <https://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>

³⁵ Australian Institute of Health and Welfare 2018, *Older Australia at a glance*, (Cat. No. AGE 87), Canberra, AIHW, <https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance>

³⁶ Productivity Commission 2011, *Disability Care and Support, Report no. 54*, Canberra, p C.3, <https://www.pc.gov.au/inquiries/completed/disability-support/report>

³⁷ Productivity Commission 2011, *Disability Care and Support, Report no. 54*, Canberra, p C.1, <https://www.pc.gov.au/inquiries/completed/disability-support/report>

³⁸ The Frail Older Persons Collaborative comprises consumers, general practitioners, geriatricians, emergency and general physicians and representatives from RACFs, non-government organisations, state wide clinical networks, nursing, allied health and Queensland Health. <https://clinicalexcellence.qld.gov.au/priority-areas/service-improvement/improving-quality-safety-and-care-older-queenslanders>

³⁹ Queensland Health, correspondence dated 23 January 2019, p 9.

Older people are also at significantly higher risk of injury due to falls, compared to the general population.⁴⁰ In 2009–10, there were an estimated 83,800 hospitalisations due to falls in people aged 65 and over (accounting for 1 in 10 days spent in hospital by older people), with the rate of fall injuries increasing with age in both sexes.⁴¹

An increase in life expectancy also means that more people are living with dementia. Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia affects thinking, behaviour and the ability to perform everyday tasks. The hallmark of dementia is the inability to carry out everyday activities as a consequence of diminished cognitive ability.⁴²

Dementia usually occurs in people who are aged 65 and over. After the age of 65 the likelihood of developing dementia doubles every five years. Currently, the prevalence of dementia in Australia is 10 per cent of people aged 65 and over, rising to 30 per cent of people 85 years and over.⁴³

In 2018, there were an estimated 376,300 Australians with dementia, nearly half of whom were aged 85 years and over. The number of people with dementia is anticipated to grow to around 900,000 by 2050.⁴⁴ In Queensland, estimates project that in 2050, approximately 215,272 people will have dementia, compared to 48,674 in 2011. This represents a 342% increase in the prevalence of dementia between 2011 and 2050.⁴⁵

People with dementia account for 52% of all residents in RACFs, compared with less than 10 per cent of all Australians over 65 years. Residents of RACFs who have dementia tend to have high care needs. For example, over three quarters of people with dementia (78.4%) living in RACFs have high-care needs with respect to behaviour (cognitive skills, wandering, verbal behaviour, physical behaviour and depression), 59.2% with activities of daily living (care needs covering nutrition, mobility, personal hygiene, toileting and continence), and 52.1% with complex health needs (e.g. use of medications, and the residents' need for the management of complex health care procedures).⁴⁶ The proportion of persons with dementia having high care needs is significantly more than the percentage of residents without dementia (38.4%, 42.4% and 50.6% respectively).⁴⁷

⁴⁰ Productivity Commission, *Caring for Older Australians*, Report No. 53, 2011, Vol 1, p 5, <https://www.pc.gov.au/inquiries/completed/aged-care/report>.

⁴¹ Australian Institute of Health and Welfare, *Australia's health 2014*, Australia's health series no. 14, Cat. no. AUS 178, Canberra, https://www.aihw.gov.au/getmedia/19dbc591-b1ef-4485-80ce-029ff66d6930/6_9-health-ageing.pdf.aspx.

⁴² Dementia Australia, *What is dementia?*, https://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia01-WhatIsDementia_english.pdf.

⁴³ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 6, https://www.gen-agedcaredata.gov.au/www_aihwwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁴⁴ Australian Institute of Health and Welfare 2012, *Dementia in Australia*, Cat. no. AGE 70. Canberra: AIHW; Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 13, https://www.gen-agedcaredata.gov.au/www_aihwwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁴⁵ Alzheimer's Australia, *Projections of Dementia Prevalence and Incidence in Queensland 2011-2050*, September 2011, p 4, <https://www.dementia.org.au/publications/access-economics-reports>.
https://www.dementia.org.au/sites/default/files/20120228_REP_QLD_Projections_of_dementia_prevalence_and_incidence_in_QLD_20112050_20111124_MS.pdf.

⁴⁶ Australian Institute of Health and Welfare, *Dementia in Australia*, 2012, AIHW Cat. no. AGE 70. Canberra, <https://www.aihw.gov.au/reports/dementia/dementia-in-australia/contents/table-of-contents>.

⁴⁷ The National Centre for Social and Economic Modelling (NATSEM), *Economic Cost of Dementia in Australia 2016-2056*, 2016, p 15, <https://www.dementia.org.au/files/NATIONAL/documents/The-economic-cost-of-dementia-in-Australia-2016-to-2056.pdf>.

Again, this will have implications for the delivery of aged and health care services. Demand for aged care services is expected to become more diverse in the future because of changing patterns of disease among the aged, including the increasing prevalence of chronic diseases and dementia.⁴⁸

Committee comment

Queensland's rapidly growing and ageing population presents challenges for aged care and health care providers. Over the next 16 years, the number of Queenslanders over 65 is expected to double, and the number of Queenslanders aged over 85 is projected to increase by 122% to over 200,000.

The state's population also remains highly decentralised. More than 40% of residents aged 65 years or older live outside of major cities. This includes over 10,000 people living in remote areas and a further 6,400 living in very remote areas. The challenge of providing care to elderly people dispersed across a large state is exacerbated by the increasing prevalence of disabilities, dementia, frailty and chronic disease among older Queenslanders.

These conditions are expected to increase demand for a more diverse range of aged care and health care services in the future.

⁴⁸ Productivity Commission, *Caring for older Australians*, Report No. 53, 2011, Vol 1, p 2, <https://www.pc.gov.au/inquiries/completed/aged-care/report>.

3 The aged care system

3.1 What is aged care?

Aged care refers to a range of services available to older people who are unable to live independently without assistance due to frailty, physical/mental disability or other age-related conditions. These services may include assistance with everyday living, help with personal care, health care and/or accommodation.⁴⁹

While aged care is often provided by informal carers, such as partners and children, approximately 80% of older people will access some form of government funded aged care before their death.⁵⁰ As people age, they are more likely to require assistance with everyday activities such as household chores and transport, with the intensity and type of aged care services required to meet the needs of older people increasing with frailty and age-related illnesses.⁵¹

For people aged 85 and over, there is a greater need for care and support due to a greater prevalence of severe or profound limitations at those ages and in the use of aged care services.⁵² According to the Aged Care Financing Authority (ACFA), the proportion of people using home care and residential care at age 85 and over is more than three times that of people aged 70 and over.⁵³

While a large percentage of older Australians will access some form of aged care, the use of aged care services is not linear, that is, there isn't necessarily a progression of care from low-level or temporary care to high-level, permanent care. People may enter at any level.⁵⁴

3.1.1 The importance of informal care

While this report focuses on the delivery of formal aged care, it is important to note that informal care makes up a significant part of the care provided to older Queenslanders. Informal care is unpaid care provided to an older and dependent person by a person with whom they have a social relationship, such as a family member, neighbour or friend. People who need help may also receive formal services from government and other organisations, with the informal (unpaid) care often complementing formal (paid) services.⁵⁵

⁴⁹ Productivity Commission, *Caring for Older Australians*, Report No. 53, 2011, Vol 1, p 4, <https://www.pc.gov.au/inquiries/completed/aged-care/report>; Royal Commission into Aged Care Quality and Safety, *Navigating the maze: an overview of Australia's current aged care system*, Background Paper 1, February 2019, p 7, <https://agedcare.royalcommission.gov.au/publications/Documents/background-paper-1.pdf>.

⁵⁰ Productivity Commission, *Caring for Older Australians*, Report No. 53, 2011, Vol 1, p 4, <https://www.pc.gov.au/inquiries/completed/aged-care/report>; Australian Institute of Health and Welfare, *Use of aged care services before death*, 2015, p 4, <https://www.aihw.gov.au/reports/aged-care/use-of-aged-care-services-before-death/contents/table-of-contents>.

⁵¹ Royal Commission into Aged Care Quality and Safety, *Navigating the maze: an overview of Australia's current aged care system*, Background Paper 1, February 2019, <https://agedcare.royalcommission.gov.au/publications/Documents/background-paper-1.pdf>.

⁵² Productivity Commission, *Caring for Older Australians*, Report No. 53, 2011, Vol 1, p 5, <https://www.pc.gov.au/inquiries/completed/aged-care/report>.

⁵³ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 7. <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵⁴ Australian Institute of Health and Welfare, Aged care, About, <https://www.aihw.gov.au/reports-data/health-welfare-services/aged-care/about>.

⁵⁵ Australian Institute of Health and Welfare, Informal carers, <https://www.aihw.gov.au/reports/australias-welfare/informal-carers>.

- 242,612 people received permanent residential aged care.⁶³

People also accessed care through flexible care programs and other aged care services. Some people received care through more than one program.⁶⁴

The total number of operational residential and flexible aged care places at 30 June 2019 was 223,041, representing an increase of 6,826 residential and flexible aged care places since 30 June 2018. At 30 June 2019, there were 106,707 people in a home care package, an increase of 14,860 since 30 June 2018.⁶⁵

3.1.3 Eligibility for government-funded aged care

The aged care system caters for Australians aged 65 and over (and Indigenous Australians aged 50 and over) who can no longer live without support in their own home. The aged care system offers a continuum of care which may be provided in people's homes, in the community and in RACFs (nursing homes) by a wide variety of providers.⁶⁶

However, while Australian Government-subsidised aged care is targeted at frail older Australians, there is no minimum age for eligibility, apart from the Commonwealth Home Support Programme (CHSP) (65 years and over, or 50 years and over for Aboriginal and Torres Strait Islander people). There are also no Australian citizenship or residency requirements to access Australian Government-subsidised aged care services.⁶⁷

3.1.4 Changing expectations of aged care services

Demand for aged care services is expected to become more diverse in the future because of:

- changing patterns of disease among the aged (including the increasing prevalence of chronic diseases and dementia), and
- a wider range of preferences and expectations (including rising preferences for independent living).⁶⁸

The Commonwealth Department of Health (Department of Health) suggests that the older population themselves will, on average, be more affluent and are likely to expect higher quality care and greater choice over how they live their lives and the care and support they receive.⁶⁹

ACFA stated in its report, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, when referring to the Baby Boomer generation:

It is reasonable to assume that they will both expect and be able to afford higher standards of residential accommodation, lifestyle amenities and quality of life than previous generations have been willing to accept. Like the current generation, however, baby boomers can be expected to

⁶³ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 11, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁶⁴ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 11, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁶⁵ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 4, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁶⁶ Queensland Health, correspondence dated 23 January 2019, p 7.

⁶⁷ Commonwealth Department of Health, correspondence dated 23 January 2019, attachment, p 9.

⁶⁸ Productivity Commission, *Caring for Older Australians*, Report No. 53, 2011, Vol 1, p 2, <https://www.pc.gov.au/inquiries/completed/aged-care/report>.

⁶⁹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 6.

*prefer to remain living in their own home for as long as possible as they age. Nevertheless, maintaining equity in access to aged care services will continue to be important and a robust safety net will continue to be necessary.*⁷⁰

It is expected that older Australians will also want to take advantage of advances in care and technology to assist them to remain independent and engaged in society for longer.⁷¹

The ACFA commented on the consequences of these trends for providers:

*To compete in this environment, however, providers will need to be more responsive in meeting consumer needs, including in particular the desire to stay at home for as long as possible, and this may require the introduction of new business models and changes in the interaction between retirement living, home care and residential care. The aged care regulatory system will also need to adapt to enable providers greater flexibility to pursue new business models and innovation.*⁷²

The AIHW has suggested that for the health system, social changes among the next generation of older people—such as greater understanding and awareness of health issues and greater expectations of health services—pose additional challenges, and may influence future models of health-care delivery and engagement.⁷³

For older Queenslanders living in regional and remote areas, it can be harder to deliver health and aged care services due to the challenges of geographic spread, low population density, limited infrastructure and the significantly higher costs of rural and remote health care delivery.⁷⁴ Similarly, people living in regional, remote and isolated areas can find it more difficult to access community and residential care services.⁷⁵

3.2 Funding of aged care

Aged care services in Australia are funded by governments (federal, state, territory and local governments), non-government organisations (charities, religious and community groups), and personal contributions from those receiving care. Governments subsidise the cost of care and recipients contribute through fees and payments.⁷⁶ However, the Australian Government is the major funder of aged care, with aged care consumers contributing to the cost of their care where able to do so.

⁷⁰ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 141, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁷¹ Productivity Commission, *Caring for Older Australians*, Report No. 53, 2011, Vol 1, p 2, <https://www.pc.gov.au/inquiries/completed/aged-care/report>.

⁷² Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 109, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁷³ Australian Institute of Health and Welfare 2014 *Australia's health 2014*. Australia's health series no. 14. Cat. no. AUS 178, p 2, https://www.aihw.gov.au/getmedia/19dbc591-b1ef-4485-80ce-029ff66d6930/6_9-health-ageing.pdf.aspx.

⁷⁴ Standing Council on Health, *National Strategic Framework for Rural and Remote Health*, 2012, p 1, https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0004/178852/National-Strategic-Framework-Rural-Remote-Health-2012.pdf.

⁷⁵ Australian Government, Productivity Commission, *Trends in aged care services: some implications*, Productivity Commission Research Paper, September 2008, p 82, https://www.pc.gov.au/__data/assets/pdf_file/0004/83380/aged-care-trends.pdf.

⁷⁶ Australian Institute of Health and Welfare, *Government spending on aged care*, <https://www.gen-agedcaredata.gov.au/Topics/Government-spending-on-aged-care>.

The Australian Government's expenditure for aged care throughout 2018–19 totalled \$19.9 billion, an increase of 10 per cent from the previous year.⁷⁷ Australian Government expenditure on aged care is projected to increase to \$24 billion by 2021-22, and projected to nearly double as a share of the economy from 1 per cent currently to around 1.7 per cent of GDP by 2055. Costs of care will continue to rise on account of growth in input costs (e.g. wages) and the increasing complexity of chronic health conditions in ageing populations.⁷⁸

In the 2019-20 budget, the Australian Government committed to funding of \$21.6 billion in 2019-20 to 'strengthen the safety, quality, access to, and integrity of Australia's aged care system'.⁷⁹

3.2.1 Aged Care Financing Authority

For decisions on aged care funding, the Australian Government receives advice from ACFA, a statutory committee established in 2012 under the *Aged Care Act 1997* (Cth) (Aged Care Act). The responsibilities and operations of ACFA are guided by the *Committee Principles 2014* made under the Aged Care Act.

According to the *Committee Principles 2014*, ACFA must provide advice to the Minister in relation to any specific issue relating to the funding and financing of aged care services. The authority also reports by 30 June each year on the impact of funding and financing arrangements on: the viability and sustainability of the aged care sector, the ability of consumers to access quality aged care, and the aged care workforce.⁸⁰

3.2.2 Consumer contributions

The majority of aged care recipients contribute to the cost of their care. Recipients may also choose to pay additional amounts to a provider to access additional levels of care or services. For example, they may 'top-up' funding available under a home care package, or purchase additional lifestyle-related services in residential care.⁸¹

In residential care, recipients contribute 85% of the single age pension towards their living expenses, paid through the Basic Daily Fee. Recipients may also be required to contribute towards their accommodation and care costs, subject to means testing.⁸²

⁷⁷ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 10, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%932018-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%932019.pdf.

⁷⁸ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 8, 22, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁷⁹ Australian Government, Budget 2019-20, Fact sheet: Supporting older Australians, https://budget.gov.au/2019-20/content/factsheets/aged_care.htm.

⁸⁰ Aged Care Financing Authority, ACFA Submission to the Royal Commission into Aged Care Quality and Safety, p 2, https://www.health.gov.au/sites/default/files/documents/2019/12/acfa-submission-to-the-royal-commission-into-aged-care-quality-and-safety_0.pdf.

⁸¹ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 13, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁸² Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 13, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

3.3 The role of the Australian Government in aged care

The Australian Government has primary responsibility for aged care policy, the provision of aged care funding through subsidies, supplements and grants, and for the regulatory framework supporting the quality and safety of aged care services and prudential regulation.⁸³

The table below sets out the roles and responsibilities of federal departments and agencies involved in aged care:

Table 4: Roles and responsibilities of federal departments and agencies

Departments/agencies	Main roles and responsibilities
Health portfolio:	
Department of Health	Policy advice, program design, allocation of residential and flexible care places, allocation of funding, information provision, regulatory framework for quality and safety, prudential regulation and compliance action
Aged Care Quality and Safety Commissioner	Handling of complaints, accreditation, and assessment and monitoring of Commonwealth funded aged care services
Aged Care Pricing Commissioner	Approval of specific payments and fees
Department of Veteran's Affairs	Veterans' Home Care Program and DVA Community Nursing Program
Department of Human Services	Administers aged care payments and means testing arrangements
Social Services Portfolio:	
Department of Social Services	Administers grants payments and agreements for aged care programs
NDIS Quality and Safeguards Commission	Administers obligations for some residential aged care providers

Source: Correspondence from Department of Health, dated 23 January 2019.

The Australian Government also provides information about aged care services through the My Aged Care contact centre and the My Aged Care website.

3.3.1 Legal framework for aged care services

The Aged Care Act and subordinate legislation (Aged Care Principles and Determinations) provide the legislative framework for home care, residential care and flexible care.⁸⁴ Some further services are provided through contractual arrangements outside of the Aged Care Act. The legislation sets out the basis for the allocation of aged care places, approval of providers and care recipients, payment of subsidies, supplements and certain grants, fees and payments, and responsibilities of approved providers of aged care services, including the quality of care to be provided.

Other aged care programs such as the Commonwealth Home Support Program (CHSP) and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program are not covered by the Aged Care Act. These programs provide grant funding to providers. These programs are governed by the CHSP

⁸³ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 6.

⁸⁴ *Aged Care Act 1997* (Cth), Division 21.

Program Manual 2018-20 and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program Manual respectively.⁸⁵

Eligibility to receive a subsidy or other funding under the Aged Care Act is conditional on compliance with the regulatory framework. To receive funding from the Australian Government under the Aged Care Act, an aged care service must be operated by an approved provider. Residential aged care services must also hold an allocation of places. Responsibility for the approval of providers has recently been transferred from the Department of Health to the Aged Care Quality and Safety Commission (see section 11.1), while the allocation of places is managed by the Department of Health in accordance with the Aged Care Act.

Under the Aged Care Act, the Australian Government-subsidised approved provider is responsible for the quality of care and services that it provides. The framework sets out the requirements to become an approved provider of aged care services, the responsibilities that approved providers must meet, and the compliance action that may be taken where responsibilities are not met. In addition, approved providers must meet relevant state and territory regulatory requirements, for example, work health and safety obligations, food regulation and building codes.

As well as the protections under general consumer law, the aged care regulatory system supports consumers through:

- the requirement that providers must give prospective new care recipients information on their rights and responsibilities; and
- a free complaints resolution service provided by the Aged Care Quality and Safety Commission.

3.3.2 Supply of aged care places

The supply of aged care places in Australia is managed by the Australian Government. It does this by specifying a national target provision ratio (the ratio) of subsidised aged care places. This ratio is based on the number of people aged 70 and over within a population. The use of the ratio is designed to allow the overall supply of services to increase in line with the ageing of the population, while also defining the total number of places/packages and, thereby, helping control the Commonwealth's expenditure on aged care.⁸⁶ Government-funded places are allocated to regions depending on how many people there are in the target population (people aged 70 and over), and the care needs of people in the region.

The overall target provision ratio comprises residential care, home care and, since 2016, restorative care places. The overall aged care provision target ratio is being adjusted to progressively increase from the target of 113 operational places per 1,000 people aged 70 and over that applied prior to 2012 to 125 by 2021-22. Over the same period the target for home care packages is increasing from 27 to 45, while the residential care target will reduce from 86 to 78. The remaining two places are for the Short Term Restorative Care Programme (STRC).⁸⁷ Home care packages were first introduced into the

⁸⁵ Australian Government, Department of Health, Commonwealth Home Support Programme (CHSP) Manual 2018–2020, <https://www.health.gov.au/sites/default/files/documents/2019/12/commonwealth-home-support-programme-chsp-manual-2018-2020.pdf>; Australian Government, Department of Health, National Aboriginal and Torres Strait Islander Flexible Aged Care Program Manual, <https://www.health.gov.au/sites/default/files/documents/2019/12/national-aboriginal-and-torres-strait-islander-flexible-aged-care-program-manual.pdf>.

⁸⁶ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 32, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁸⁷ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 6, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

overall aged care target provision ratio in the early 1990s and since then successive Governments have gradually increased home care as a proportion of the overall target provision ratio.⁸⁸

At 30 June 2019, the ratio is 79.6 aged care places for every 1,000 people aged 70 years and over (up from 79.2 in 2018).⁸⁹

As the number of aged care places increases, the balance of care types within the ratio will also change in response to consumer preference to stay at home, where possible, and programs to enable senior Australians to regain independence and autonomy rather than entering long term care prematurely.⁹⁰

The Australian Government does not regulate the supply of home support services (CHSP) in the same way as it does home care and residential care, as these services are provided through grant-funding arrangements, although the supply is affected by overall funding levels.⁹¹ The target ratio approach applied to home care packages and residential care places does not apply to the supply of care through the CHSP. Instead, CHSP funding is subject to an annual capped funding allocation, and CHSP providers are grant funded to provide contracted home support services. Consumers who are assessed as eligible through their Regional Assessment Service to receive CHSP services can then access those services through a provider who delivers the services for which they have been assessed.⁹²

3.3.2.1 *Allocation of residential aged care places*

New residential care places are allocated to approved providers through the Aged Care Approvals Round (ACAR), which is a competitive process set out in the legislation. This process enables both prospective and existing approved providers of aged care to apply for a range of new Australian Government-funded aged care places (residential aged care places and Short Term Restorative Care places). The ACAR may also offer financial assistance in the form of a capital grant for eligible providers. ACAR rounds are generally held every 12 to 18 months and the timing for the opening of each round is a matter for the Australian Government.⁹³

⁸⁸ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, pp 31-32, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁸⁹ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 4, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf; Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 4, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁹⁰ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 4, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf

⁹¹ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 4, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁹² Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 34, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>

⁹³ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 5, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

In the 2018-19 ACAR, Queensland received 4,289 new residential places with estimated annual recurrent funding of \$300.5 million, and \$11.1 million in capital grants.⁹⁴

3.3.2.2 *Allocation of home care packages*

The number of packages released at each level takes into account:

- the number of new packages that are available (having regard to the phased increase in the target home care provision ratio)
- the number of packages that consumers have exited or not accepted in previous weeks, and
- the amount of unspent Commonwealth funds that have been returned when consumers leave home care.⁹⁵

The total number of packages increases each year with the distribution across the four levels set by the Australian Government.⁹⁶ However, the number of packages at each funding level will continue to be capped in line with the aged care target provision ratio and the available budget.⁹⁷

Under the Aged Care Act, the Australian Government then provides the subsidy to an approved provider of home care, chosen by the client, to coordinate a package of care, services, and case management to meet their individual needs.⁹⁸

3.4 The role of state and territory governments

State and territory governments employ and manage Aged Care Assessment Teams (ACATs) which assess people's eligibility for particular types of aged care services.⁹⁹ Two of the flexible aged care programs, the Transition Care Programme and the Multi-Purpose Services Program, are jointly funded by the states and territories and the Australian Government.¹⁰⁰

Queensland Health is contracted by the Australian Government to manage the Aged Care Assessment Program. Assessments are conducted by ACATs in Hospital and Health Services (HHSs) across Queensland.¹⁰¹ Queensland Health is also an Approved Provider under the Aged Care Act for State-operated aged care services. Aged care services comprise residential aged care facilities, home care packages and flexible care services including transition care services and multipurpose health services.¹⁰²

⁹⁴ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 5, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁹⁵ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 37, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁹⁶ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 5, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁹⁷ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 37, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁹⁸ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 6, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁹⁹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 7.

¹⁰⁰ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 7.

¹⁰¹ Queensland Health, correspondence dated 23 January 2019, p 7.

¹⁰² Queensland Health, correspondence dated 23 January 2019, p 7.

Queensland Health operates 16 residential aged care facilities, across seven HHSs, with 1,112 places. This represents approximately three per cent of residential aged care places in Queensland. A list of facilities operated by Queensland Health are at **Appendix A**.

The remaining 97 per cent of places are provided by non-government and private organisations. In addition, Queensland Health operates 33 multipurpose health services, with 542 places across Queensland. Queensland Health also contributes to the funding of the Transition Care Program (an agreed 25 per cent with the Australian Government) for 733 allocated transition care places across Queensland.¹⁰³

States and territories also have broader regulatory and investigatory functions that apply to aged care providers, such as in the areas of building safety, food regulation, work health and safety, and coronial and police investigations.¹⁰⁴

3.5 The role of local government

Generally, local governments (councils) have responsibility for providing the local environment in which older people live, and for providing a range of supporting services for older people. Local governments are also responsible for the planning frameworks that govern building, extension and upgrading of aged care and retirement facilities, thus influencing the supply of suitable housing options for the ageing population.¹⁰⁵

Many local governments in Queensland have seniors' strategies and/or services which focus specifically on the needs of their older populations, and opportunities for making the built and social environments more accessible and supportive, and keeping older people healthier, physically active and socially engaged.¹⁰⁶

However, the following local governments were providing varying forms of aged care services in Queensland as of 30 June 2018:

- Aurukun Shire Council
- Barcaldine Regional Council
- Blackall Tambo Regional Council
- Dalrymple Villa Inc
- Flinders Shire Council
- Hope Vale Aboriginal Council
- Kowanyama Aboriginal Shire Council
- Mapoon Aboriginal Council
- Napranum Aboriginal Council
- Pormpuraaw Community Council
- Richmond Shire Council
- Western Downs Regional Council
- Winton Shire Council
- Wujal Wujal Aboriginal Shire Council.¹⁰⁷

¹⁰³ Queensland Health, correspondence dated 23 January 2019, p 8.

¹⁰⁴ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 7.

¹⁰⁵ Queensland Health, correspondence dated 23 January 2019, p 8.

¹⁰⁶ Queensland Health, correspondence dated 23 January 2019, p 8.

¹⁰⁷ GEN Aged Care Data, Aged Care Services List, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/2018_service_data/QLD-service-list-at-30-June-2018.pdf.

3.6 Other reviews of aged care

The Australian aged care system has been the subject of a number of major inquiries and reviews and has undergone significant reform over the past twenty years. In 1997, the Australian Government introduced a structural reform package into the residential aged care sector. According to the National Aged Care Alliance, the major elements of the package were:

*...the unification of nursing home and hostels into one system, greater reliance on resident contributions to fund the sector, and the introduction of a new standards and accreditation system. The changes affected both recurrent and capital funding for residential aged care services.*¹⁰⁸

Prior to this, more intensive care services for older people at home had also been increased.¹⁰⁹

Subsequent to these reforms, further reviews were undertaken.¹¹⁰ The results of these reviews led to the view that further reforms of the aged care system were needed.

In 2009 the Productivity Commission was asked to develop detailed options for redesigning Australia's aged care system to ensure it could meet the challenges facing it in coming decades.¹¹¹ The terms of reference identified a number of challenges to the system, including:

- the ageing of the Australian population and increasing demand on aged care
- significant shifts in the type of care required by older Australians due to factors including changes in patterns of disease and increasing acuity, changes in older people's preferences, changes in the affluence of older people, reduced access to carers, and the diverse geographic spread of the population, and
- workforce challenges due to workforce availability and parity issues.¹¹²

The Productivity Commission released its report in 2011, finding that:

- the aged care system was difficult to navigate
- services and consumer choice were limited
- quality was variable
- the coverage of needs, pricing, subsidies and user co-contributions was inconsistent or inequitable, and
- workforce shortages were exacerbated by low wages and that some workers had insufficient skills.¹¹³

¹⁰⁸ National Aged Care Alliance, *Residential Aged Care Funding: Second Report*, October 2001, p 5 <https://naca.asn.au/wp-content/uploads/2018/11/Residential-aged-care-funding-Research-report-October-2001.pdf>.

¹⁰⁹ Productivity Commission, *Caring for Older Australians*, Inquiry Report No. 53, 2011, Vol 1, p 15, <https://www.pc.gov.au/inquiries/completed/aged-care/report>.

¹¹⁰ These reviews included the National Health and Hospitals Reform Commission's report *A Healthier Future For All Australians*, the Senate Standing Committee on Finance and Public Administration's *Inquiry into residential and community aged care in Australia*, and the Productivity Commission's 2009 *Annual Review of Regulatory Burdens on Business: Social and Economic Infrastructure Services*.

¹¹¹ Productivity Commission, *Caring for Older Australians*, Inquiry Report No. 53, 2011, Vol 1, p XXIII, <https://www.pc.gov.au/inquiries/completed/aged-care/report>.

¹¹² Productivity Commission, *Caring for Older Australians*, Inquiry Report No. 53, 2011, Vol 1, p V, <https://www.pc.gov.au/inquiries/completed/aged-care/report>.

¹¹³ Productivity Commission, *Caring for Older Australians*, Inquiry Report No. 53, 2011, Vol 1, p XXII, <https://www.pc.gov.au/inquiries/completed/aged-care/report>.

The report made 58 comprehensive recommendations, proposing significant changes to the aged care system. These changes were designed to move the aged care system towards a consumer-driven and market-based system, while maintaining oversight of quality and safety standards.¹¹⁴

The report called for structural reform of the aged care sector, with proposed changes focusing on:

- consumer directed care
- improving access
- quality and choice of services
- funding of aged care
- care delivery
- reforming the regulatory framework
- financial sustainability
- improving the interface with disability and health systems, and
- increasing the scope for innovation of delivery including improved use of technology.¹¹⁵

The Australian Government incorporated some of the Productivity Commission's recommendations in its 2012 *Living Longer Living Better* (LLL) reform package. These reforms were designed to be implemented over five years to deliver more support and care at home, additional home and residential care places, a focus on greater consumer choice and control, greater recognition of diversity and support to carers.¹¹⁶ The longer term goal was to create a more flexible and integrated aged care system driven by consumer choice, with less government regulation.¹¹⁷

In 2013 the LLL reform Bills were introduced, including amendments to the Aged Care Act. The key changes resulting from these reforms included the following:

- requiring consumers to contribute equitably to the cost of their care and accommodation
- means testing on income in Home Care and income and assets in residential care
- placing a greater focus on individualised care
- introducing Consumer Directed Care (CDC) Home Packages
- establishing the *My Aged Care* website and call centre to help people navigate the system¹¹⁸

¹¹⁴ Deeble Institute for Health Policy Research, The impact of the home care reforms on the older person, the aged care workforce and the wider Health System, Issues Brief No. 27, p 5, https://ahha.asn.au/sites/default/files/docs/policy-issue/deeble_issues_brief_no._27_home_care_reforms.pdf.

¹¹⁵ Parliament of Australia, Parliamentary Library Briefing Book – 45th Parliament, Aged care—reforming the aged care system, https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/BriefingBook45p/AgedCare.

¹¹⁶ National Seniors Australia, Aged Care Reform – Living Longer Living Better, <https://nationalseniors.com.au/uploads/140601-NationalSeniors-FactSheet-AgedCareReform.pdf>.

¹¹⁷ Parliament of Australia, Parliamentary Library Briefing Book – 45th Parliament, Aged care—reforming the aged care system; COTA Australia, *Keep fixing Australia's aged care system: taking the next steps in tandem with the Royal Commission*, Position Paper, September 2018.

¹¹⁸ Parliament of Australia, Parliamentary Library Briefing Book – 45th Parliament, Aged care—reforming the aged care system, https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/BriefingBook45p/AgedCare; COTA Australia, *Keep fixing Australia's aged care system: taking the next steps in*

- removal of the distinction between low and high care in residential care
- more transparent accommodation payment levels and a choice of payment method.¹¹⁹

In addition, a comprehensive review of these changes was included in the *Aged Care (Living Longer Living Better) Act 2013* (Cth).

It has been noted that while the LLLB package adopted some of the recommendations made by the Productivity Commission, it did not structurally reform the financing of aged care, nor did it lift restrictions on the supply and allocation of aged care places.¹²⁰ The recommendation to establish a separate aged care commission and the separation of policy and funding roles were also neglected by the LLLB reform package.¹²¹

In April 2015, the Aged Care Sector Committee, which commenced in 2014, was tasked with developing a roadmap to advise on future directions for aged care.¹²² The Aged Care Sector Committee comprises key stakeholders in the aged care sector with the aim of working in partnership on the development and implementation of aged care policy by the Australian Government, with David Tune AO as Chair.

The Aged Care Roadmap (Roadmap), delivered to the Minister for Health and Aged Care in April 2016, presented the Age Care Sector Committee's views on the short, medium and long term actions required to transform the current aged care system into a sustainable, consumer driven and market based system. The key features of the system proposed by the Roadmap are:

- consumers, their families and carers are proactive in preparing for their future care needs and are empowered to do so
- a single government operated assessment process that is independent and free, and includes assessment of eligibility, care needs, means and maximum funding level
- regardless of cultural or linguistic background, sexuality, life circumstance or location, consumers can access the care and support that they need
- the community is dementia aware and dementia care is integrated as core business throughout the aged care system
- a single aged care and support system that is market based and consumer driven, with access based on assessed need

tandem with the Royal Commission, Position Paper, September 2018,
<https://www.cota.org.au/publication/keep-fixing-australias-aged-care-system/>.

¹¹⁹ Parliament of Australia, Parliamentary Library Briefing Book – 45th Parliament, Aged care—reforming the aged care system,
https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/BriefingBook45p/AgedCare.

¹²⁰ Parliament of Australia, Parliamentary Library Briefing Book - 44th Parliament, Reforming Australia's aged care system: are we there yet?,
https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/BriefingBook44p/AgedCare.

¹²¹ Australian Law Reform Commission, *Elder Abuse—A National Legal Response*, Final Report, 2017, p 118, <https://www.alrc.gov.au/publication/elder-abuse-a-national-legal-response-alrc-report-131/>. In January 2019 the Aged Care Quality and Safety Commission was established following a similar recommendation in 2017 by the Carnell-Paterson *Review of the National Aged Care Quality Regulatory Processes*.

¹²² Australian Government, Department of Health, Aged Care Roadmap,
https://www.health.gov.au/sites/default/files/aged-care-roadmap_0.pdf.

- a single provider registration scheme that recognises organisations registered or accredited in similar systems, and that has a staged approach to registration depending on the scope of practice of the providers
- sustainable aged care sector financing arrangements where the market determines price, those that can contribute to their care do, and government acts as the 'safety net' and contributes when there is insufficient market response
- a well-led, well-trained workforce that is adept at adjusting care to meet the needs of older Australians, and
- greater consumer choice drives quality and innovation, responsive providers and increased competition, supported by an agile and proportionate regulatory framework.¹²³

The Roadmap broadly aligned with and continued the changes that commenced with the Productivity Commission's recommendations.¹²⁴ Although the Roadmap is not a government policy document, the Department of Health has indicated that the Australian Government has shown support for the Roadmap's final destination of a sustainable, consumer-driven and market-based system, and it was considered in the aged care Budget measures announced in May 2018.¹²⁵

Subsequent to the release of the Roadmap, the review legislated under the LLLB reforms was undertaken by David Tune, starting on 22 September 2016 and completed on 31 July 2017.¹²⁶ The Aged Care Legislated Review (the Tune Review) considered the impacts and effectiveness of the LLLB reforms implemented over the previous five years, including changes to the supply and demand for aged care services, means testing and accommodation payments arrangements, changes to how consumers access the aged care system, and workforce issues. It also made recommendations for future reform to the aged care system.¹²⁷

The Tune Review found that reforms had been effective overall, but further reforms were needed to move towards a system which is more consumer-centred and sustainable. It included 38 recommendations for future reform to the aged care system.¹²⁸

Key recommendations from the Tune review included:

- giving older people in residential care ownership of their packages so they can choose the best provider and transfer to another if they are not happy with their care

¹²³ Aged Care Sector Committee, *Aged Care Roadmap*, March 2016, p 3, <https://www.health.gov.au/resources/publications/aged-care-roadmap>.

¹²⁴ Australian Government, Department of Health, *Aged Care Roadmap*, https://www.health.gov.au/sites/default/files/aged-care-roadmap_0.pdf.

¹²⁵ Australian Government, Department of Health, Aged Care Sector Committee, <https://www.health.gov.au/committees-and-groups/aged-care-sector-committee>; Parliament of Australia, Parliamentary Library, FlagPost blog, *Aged Care Roadmap: a guide to the future of aged care?*, https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/FlagPost/2016/May/aged-care-roadmap.

¹²⁶ <https://agedcare.health.gov.au/reform/aged-care-legislated-review>.

¹²⁷ David Tune AO PSM, *Legislated Review of Aged Care 2017*, p 6, <https://www.health.gov.au/sites/default/files/legislated-review-of-aged-care-2017-report.pdf>.

¹²⁸ David Tune AO PSM, *Legislated Review of Aged Care 2017*, p 12, <https://www.health.gov.au/sites/default/files/legislated-review-of-aged-care-2017-report.pdf>.

- discontinuing the Aged Care Approvals Round [ACAR]¹²⁹ for residential care places, instead assigning places directly to the consumers within the residential care cap, with changes to take effect two years after announcement by government
- increasing access to home care packages, especially higher-level packages
- increasing access to high level (level 5) home care packages by allowing for the temporary allocation of a home care package where there is a residential care place that is not being used
- improving the capacity and user friendliness of the My Aged Care website, contact centre and assessment services including the publishing of comparable home service prices on My Aged Care
- introducing aged care system navigators and outreach services to assist consumers who have difficulty engaging through the existing My Aged Care channels
- improving the sustainability of aged care to meet demand in the future.¹³⁰

According to the ACFA, the Tune Review recommendations were designed to:

...move aged care further towards a consumer-focused demand-driven system and to trigger changes that are prerequisites for a fully consumer-driven aged care system. Some do this by targeting better consumer access through better understanding of, and response to, demand, some by improving information and assessment, some by improving sustainability, and others by supporting greater equity in consumer contributions. The latter includes greater consistency of fee arrangements within and across care types and improved equity in the treatment of different forms of income and assets.¹³¹

It should be noted that, at the time of preparing this report, the Australian Government had not implemented all of the key recommendations listed above.

In addition to the Tune Review, an independent Review of National Aged Care Quality Regulatory Processes led by Ms Kate Carnell AO and Professor Ron Paterson ONZM (Carnell Paterson Review) was announced by the Australian Government in response to the Oakden Report, which identified failures in the quality of care delivered at the Oakden Older Persons Mental Health Service in South Australia.¹³²

The Carnell Paterson Review examined why regulatory processes did not adequately identify the systemic and longstanding failures of care documented in the Oakden Report, and identified improvements to the regulatory system designed to increase the likelihood of immediate detection, and swift remediation by providers.¹³³

¹²⁹ The Aged Care Approvals Round (ACAR) is the Australian Government's process for allocating and distributing new aged care places and capital grants to new and existing approved providers of aged care providers according to the requirements of the *Aged Care Act 1997* (Cth). For further information see the Department of Health's *2018-19 ACAR Essentials Guide*, available at www.health.gov.au.

¹³⁰ David Tune AO PSM, *Legislated Review of Aged Care 2017*, pp 13-17, <https://www.health.gov.au/sites/default/files/legislated-review-of-aged-care-2017-report.pdf>.

¹³¹ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, pp 29-30, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

¹³² Australian Government, Department of Health, Review of National Aged Care Quality Regulatory Processes, <https://www.health.gov.au/health-topics/aged-care/aged-care-reforms-and-reviews/review-of-national-aged-care-quality-regulatory-processes>.

¹³³ Australian Government, Department of Health, Review of National Aged Care Quality Regulatory Processes, <https://www.health.gov.au/health-topics/aged-care/aged-care-reforms-and-reviews/review-of-national-aged-care-quality-regulatory-processes>.

The Carnell Paterson Review, provided to the Minister in October 2017, made 10 recommendations, the first being to establish an independent Aged Care Quality and Safety Commission to centralise accreditation, compliance and complaints handling. The Aged Care Quality and Safety Commission would be responsible for:

- developing and managing a centralised database for real-time information sharing
- implementing a star-rated system for public reporting of provider performance
- supporting consumers and their representatives to exercise their rights.¹³⁴

The other recommendations included:

- all residential aged care services in receipt of Commonwealth funding being required to participate in the National Quality Indicators Program
- enacting a serious incident response scheme (SIRS) for aged care
- aged care standards limiting the use of restrictive practices in residential aged care
- ongoing accreditation, with unannounced visits, to assure safety and quality of residential aged care
- ensuring that assessment against standards is consistent, objective and reflective of current expectations of care, and
- enhancing complaints handling.¹³⁵

Following the release of the review, the Australian Government announced broad support for the direction of the report, and the replacement of announced re-accreditation audits with unannounced audits in residential aged care services.¹³⁶

The Australian Government also announced:

- the establishment of a new independent Aged Care Quality and Safety Commission from 1 January 2019
- enhanced risk profiling of aged care providers, to inform the frequency and rigour of visits and to ensure failures are quickly identified and rectified by providers
- the development of options, in consultation with the sector, for a Serious Incident Response Scheme to ensure the right systems are in place to identify an incident and prevent it from occurring again
- the introduction of a performance rating against the new quality standards
- the development of a user-friendly provider comparison tool on the My Aged Care Website.¹³⁷

¹³⁴ Ms Kate Carnell AO & Professor Ron Paterson ONZM, Review of National Aged Care Quality Regulatory Processes, October 2017, pp xi-xiii, <https://www.health.gov.au/resources/publications/review-of-national-aged-care-quality-regulatory-processes-report>.

¹³⁵ Ms Kate Carnell AO & Professor Ron Paterson ONZM, Review of National Aged Care Quality Regulatory Processes, October 2017, pp xi-xiii, <https://www.health.gov.au/resources/publications/review-of-national-aged-care-quality-regulatory-processes-report>.

¹³⁶ Australian Government, Department of Health, Review of National Aged Care Quality Regulatory Processes, <https://www.health.gov.au/health-topics/aged-care/aged-care-reforms-and-reviews/review-of-national-aged-care-quality-regulatory-processes>.

¹³⁷ Australian Government, Department of Health, Review of National Aged Care Quality Regulatory Processes, <https://www.health.gov.au/health-topics/aged-care/aged-care-reforms-and-reviews/review-of-national-aged-care-quality-regulatory-processes>.

3.7 Aged Care reforms

As a result of these reviews, the aged care industry has undergone substantial change in recent years to improve the sustainability of aged care services and increase consumer choice and control.¹³⁸ The reforms since 2012 are summarised below according to the care type they relate to, that is, the Commonwealth Home Support Programme, home care, residential care or across all these programs. Information on these programs can be found in chapters 6 to 8.

Commonwealth Home Support Programme (CHSP):

- from 1 July 2015, the CHSP commenced by combining the former Commonwealth-State Home and Community Care (HACC) programs in all states and territories except Victoria and Western Australia, and the Commonwealth National Respite for Carers, Day Therapy Centres and Assistance with Care and Housing for the Aged programs
- Victoria transitioned their HACC services to the CHSP on 1 July 2016 and Western Australia transitioned to the CHSP on 1 July 2018, and
- Regional Assessment Services were established in 2015 to assess eligibility for CHSP services.¹³⁹

Home care:

- new home care packages (levels 1-4) commenced from 1 August 2013
- income testing with subsidy reduction, including annual and lifetime caps, commenced on 1 July 2014
- Australian Aged Care Quality Agency begins reviewing home care services from July 2014
- all packages required to be CDC [consumer directed care], with individualised budgets, from 1 July 2015
- creation of a consistent National Prioritisation System to assign home care packages
- home care packages assigned to the consumer rather than allocated to the provider
- home care providers required to publish their current pricing information on the My Aged Care Service Finder, from 30 November 2018
- home care providers required to publish their pricing information in a new standardised schedule from 1 July 2019.¹⁴⁰

Residential care:

- new means testing (combining income and assets test), including annual and lifetime caps, commenced on 1 July 2014

¹³⁸ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 19.

¹³⁹ Aged Care Financing Authority, *Seventh Report on the Funding and Financing of the Aged Care Industry – 2019*, p 16, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

¹⁴⁰ Aged Care Financing Authority, *Seventh Report on the Funding and Financing of the Aged Care Industry – 2019*, pp16-17, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>; Deeble Institute for Health Policy Research, The impact of the home care reforms on the older person, the aged care workforce and the wider Health System, Issues Brief No. 27, p 6, https://ahha.asn.au/sites/default/files/docs/policy-issue/deeble_issues_brief_no._27_home_care_reforms.pdf.

- new accommodation payment arrangements from 1 July 2014 which allow market-based accommodation prices for all non-supported residents, accompanied by consumer choice to pay by lump sum, daily payment or a combination of both
- requirements for providers to publish the maximum price they charge for accommodation and extra services, from 1 July 2014
- higher accommodation supplement payable for supported residents in residential care facilities that were newly built or significantly refurbished since 20 April 2012
- creation of an Aged Care Pricing Commissioner position in October 2013, and
- rental income from the former home became assessable for all residents who enter care from 1 July 2016 (formerly exempt for residents who made a daily payment for their accommodation).¹⁴¹

Cross-program:

- overall target provision ratio for Government subsidised aged care places to increase from 113 places for every 1,000 people aged 70+ to 125 places between 2012-13 and 2021-22
- My Aged Care website and contact centre launch as an information service in July 2013
- My Aged Care expands to include assessment, referral and a central client record from July 2015
- creation of a single budget item for home care packages and residential care places from 1 July 2018 that allows flexibility for the Government to direct available funding to home care or residential care in response to consumer preferences
- establishing the Aged Care Quality and Safety Commission from January 2019 and the commencement of a single set of quality standards across all aged care from 1 July 2019
- from 1 July 2019, all Commonwealth subsidised residential care facilities must collect and provide clinical quality indicator data to the Department of Health through the National Aged Care Quality Indicator Program¹⁴²
- from 1 July 2019, the new Charter of Aged Care Rights will provide the same rights to all consumers, regardless of the type of Commonwealth subsidised care and services they receive, and
- further improvements to My Aged Care in 2018-19 and 2019-20.¹⁴³

3.8 Royal Commission into Aged Care Quality and Safety

The Royal Commission into Aged Care Quality and Safety (the Royal Commission) was established on 8 October 2018, with a requirement to provide an interim report by 31 October 2019, and a final report

¹⁴¹ Aged Care Financing Authority, *Seventh Report on the Funding and Financing of the Aged Care Industry – 2019*, p 17, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

¹⁴² The program had initially started in 2016 as a voluntary program.

¹⁴³ Aged Care Financing Authority, *Annual Report on the Funding and Financing of the Aged Care Industry – 2019*, p 17, <https://www.health.gov.au/sites/default/files/documents/2019/11/seventh-report-on-the-funding-and-financing-of-the-aged-care-industry-july-2019.pdf>; Deeble Institute for Health Policy Research, *The impact of the home care reforms on the older person, the aged care workforce and the wider Health System*, Issues Brief No. 27, p 6, https://ahha.asn.au/sites/default/files/docs/policy-issue/deeble_issues_brief_no._27_home_care_reforms.pdf.

by 30 April 2020.¹⁴⁴ The Royal Commission is looking at the quality of aged care services in Australia, and the future challenges and opportunities for delivering accessible, affordable and high quality aged care services that are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care.

The Commission of inquiry is required and authorised to inquire into the following matters:

- a. the quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;
- b. how best to deliver aged care services to:
 - i. people with disabilities residing in aged care facilities, including younger people; and
 - ii. the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services;
- c. the future challenges and opportunities for delivering accessible, affordable and high quality aged care services in Australia, including:
 - i. in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and
 - ii. in remote, rural and regional Australia;
- d. what the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;
- e. how to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters;
- f. how best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure;
- g. any matter reasonably incidental to a matter referred to in paragraphs (a) to (f) or that [the Commissioners] believe is reasonably relevant to the inquiry.¹⁴⁵

Under the committee's terms of reference, the committee was tasked with considering:

...in relation to aged care, the terms of reference and submissions made to the Australian Government's Royal Commission into the Quality and Safety of Aged Care and, in recognising the Commission will occur in parallel, how to proactively work with the Commission to ensure an appropriate exchange of information to inform the conduct of the inquiry...

The committee met with the Commissioners Ms Lynelle Briggs AO and the late The Honourable Richard Tracey AM RFD QC on 5 August 2019, and also shared information with the Commission as appropriate, governed by both the inquiry's and Commissions' terms of reference.

On 31 October 2019, the Interim Report of the Royal Commission into Aged Care (Interim Report) was handed down. The Interim Report, entitled *Neglect*, found that the aged care system fails to meet the

¹⁴⁴ Royal Commission into Aged Care Quality and Safety, <https://agedcare.royalcommission.gov.au/Pages/default.aspx>.

¹⁴⁵ Royal Commission into Aged Care Quality and Safety, Terms of Reference, <https://agedcare.royalcommission.gov.au/Pages/Terms-of-reference.aspx>.

needs of older citizens in the delivery of safe and quality care. The Interim Report also lays the foundations for the fundamental reform and redesign of Australia's aged care system.¹⁴⁶

The Royal Commission's final report will make recommendations on reform and transformation of the aged care system in Australia. However, the Interim Report identified three areas which the Commissioners believe require immediate action:

- to provide more Home Care Packages to reduce the waiting list for higher level care at home
- to respond to the significant over-reliance on chemical restraint in aged care, including through the seventh Community Pharmacy Agreement, and
- to stop the flow of younger people with disability going into aged care, and expediting the process of getting those younger people who are already in aged care out.¹⁴⁷

The Australian Government responded to the Interim Report advising it will deliver a \$537 million funding package across the identified three priority areas, including:

- investing \$496.3 million for an additional 10,000 home care packages
- providing \$25.5 million to improve medication management programs to reduce the use of medication as a chemical restraint on aged care residents and at home, and new restrictions and education for prescribers on the use of medication as a chemical restraint
- delivering \$10 million for additional dementia training and support for aged care workers and providers, including to reduce the use of chemical restraint, and
- investing \$4.7 million to help meet new targets to remove younger people with disabilities from residential aged care.¹⁴⁸

Committee comment

Aged care

The incidence of disabilities among the state's older age groups is significant. Many older Queenslanders depend on informal aged care rather than government-subsidised aged care. This informal care, while mostly unpaid, is invaluable to those individuals receiving it and to the wider community.

Most older people (95%) continue to live in their own homes – known as ageing in place. Similarly, most aged care is also delivered to people in private homes or other community settings. The remainder of older people receiving aged care live in care accommodation such as nursing homes or, in modern terminology, residential aged care facilities. Based on assessments for care, around half of all residents in aged care facilities have dementia.

The need for aged care, and the intensity of care that is required, increases markedly with age. Between the ages of 70 and 85 years, there is a tripling in the proportion of people using home care or residential aged care.

¹⁴⁶ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

¹⁴⁷ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 10, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

¹⁴⁸ The Hon Scott Morrison MP, Prime Minister of Australia, 'Response to Aged Care Royal Commission Interim Report', media release, 25 November 2019, <https://www.pm.gov.au/media/response-aged-care-royal-commission-interim-report>.

Future expectations of aged care services are also evolving. Queenslanders needing aged care, or those supporting them in future, are likely to be more aware of health issues and more willing to take advantages of advances in technology and care. It is also likely that people will continue to prefer to remain in their own homes as they age.

The role of government in aged care

Policy development, funding and regulation of Australia's aged care system is primarily the responsibility of the Australian Government.

Within the Queensland Government, Queensland Health and the hospital and health services provide a range of assessment services to support the Australian Government's aged care programs. The Queensland Government is also an approved provider of aged care services. Around 3% of all aged care places in Queensland are in government run facilities.

Eight local governments and seven Aboriginal councils in Queensland also provide aged care services.

Previous and current reviews of aged care

The aged care system in Australia has been reviewed and reformed almost constantly since at least the mid-1990s with each review making substantial, and often similar, recommendations to improve the aged care system. Not all of the recommendations from these reviews have been implemented, despite successive reviews supporting similar approaches or addressing similar gaps.

These reviews have articulated very clearly the dual challenges of rapidly increasing demand for aged care services and, within that demand, a growing need for high care services, particularly residential aged care service, as the number of people aged 80 and over increases with rising life expectancy in Australia. Past reviews have also highlighted the challenges for the Australian Government to design, fund and deliver affordable aged care services that meet the expectations and requirements of people in care.

The Royal Commission into Aged Care Quality and Safety has made a timely contribution to the public debate about the fragmentation of aged care quality and safety and opportunities for future reform. The committee maintained open dialogue with commissioners and staff from the Royal Commission during its inquiry. A delegation from the committee met with commissioners, Honourable Richard Tracey AM RFD QC and Ms Lynelle Briggs AO, and Official Secretary to the Royal Commission, Dr James Popple, in Brisbane on 5 August 2019. In the spirit of collaboration, the committee also resolved to share evidence gathered during its inquiry with the Royal Commission.

The committee particularly acknowledges the invaluable contribution made by Commissioner Richard Tracey who passed away on 11 October 2019.

4 Issues with aged care funding and interfaces between aged care and other sectors

This chapter and following chapters discuss the issues raised with the inquiry concerning the delivery of aged care. It begins with a discussion of concerns raised with the committee about the funding of aged care services and the interfaces between aged care and other sectors and areas of government.

4.1 Issues with funding of aged care services

A number of submissions raised concerns about the funding of aged care, including the amount of funding and the inflexibility and focus of the current funding model. Evidence provided to the inquiry on funding specifically in relation to RACFs can be found at section 7.2, and on home care and home support at section 6.4.

Some stakeholders attributed the inadequacy of the funding to the current funding model, which it was claimed does not reflect the cost of providing aged care services and limits the quality of care that can be provided.¹⁴⁹

Ms Suzanne Greenwood, Chief Executive Officer of Catholic Health Australia, raised an issue identified by a number of stakeholders regarding the future of aged care funding, stating:

*Currently the prospects for elderly Australians needing quality aged-care services are uncertain because there is no federal funding plan that is going to cater for the projected two million Australians who are going to be over the age of 85 by the year 2055.*¹⁵⁰

For example, St Vincent's Health Australia (SVHA) submitted that a lack of funding is a significant barrier to providing quality care. SVHA stated:

The Aged Care Funding Instrument (ACFI) provides a basic standard of care and services but in our experience it is insufficient to meet rising community expectations. Exacerbated by indexation arrangements, it is also failing to keep pace with sector-wide wage movements. For example, it is difficult under the current funding model to build additional GP, specialist, allied health, and mental health/social work support into care models.

*In relation to Home Care, SVHA advocates that additional case management funding should be provided to help support and cover GP and service providers time to prepare and coordinate care to individuals.*¹⁵¹

In their submission, SVHA suggested that future funding and systems should have better flexibility to support the range of care needed when the demand arises so resident's and people ageing in their homes have their needs met.¹⁵²

Anglicare Australia Network submitted that the current funding model conceptualises person-centred care in economic terms, where resources for care are perceived as scarce and people are considered solely as consumers, and advised that this approach:

...is narrow and potentially limiting when envisioning the best quality of care for the elderly. Encouraging people to see themselves in this consumer role can drive a focus on price rather than quality of care. It can also exacerbate or create conflicts regarding the ability of experts to give people the best advice about their care, as a transactional focus can lead to assumptions that recommendations that cost more are driven by a profit motive, not care for the person...The

¹⁴⁹ See, for example, submissions 2107, 1213, 1229, 1301, 1354.

¹⁵⁰ Public hearing transcript, Brisbane, 4 July 2019, p 66.

¹⁵¹ Submission 1280, p 16.

¹⁵² Submission 1280, p 13.

*current funding quantum and models, however, hamper our efforts as they are based on a premise of maximising funding efficiency over quality of care.*¹⁵³

Queensland Primary Health Networks (PHNs) also suggested that the current funding models, along with the cross-jurisdictional delivery of aged care (hospital, community care, primary health care, residential), do not support coordinated and integrated care as an elderly person moves along the care continuum. They argued that as an alternative, value based care and outcomes commissioning would allow greater flexibility to meet the needs of individuals and populations to achieve better health outcomes and lower costs.¹⁵⁴

Some stakeholders advised that because the current funding model doesn't adequately reflect the cost of care, a significant proportion of aged care providers are operating at a loss.

Leading Age Services Australia (LASA), the national peak body representing all providers of age services across residential care, home care and retirement living, informed the committee that there is a:

*...funding emergency in residential aged care, which sees an estimated 43 per cent of facilities currently operating at a loss, with even greater pressure being experienced by facilities operating in rural and remote locations.*¹⁵⁵

LASA also stated that the inadequacy of the current funding model has led to 'the unacceptable impact on older Australians that sees more than 120,000 older Australians waiting, sometimes for more than year, to receive essential care and services in their home'.¹⁵⁶

Churches of Christ similarly submitted:

*Consumer expectations of care and staffing standards are increasing. Families of seniors are significantly more likely to articulate their expectations and concerns and expect prompt response to any care or services they consider sub-standard. These heightened community expectations are creating tensions and financial pressures in the highly regulated RAC environment with over 40 % of providers currently operating at a financial loss. The Commonwealth Govt continues to issue further Residential Aged Care bed licenses based on identified need in the community. For these licenses to then become operating residential aged care services, the financial viability of RAC will need to improve.*¹⁵⁷

The Lutheran Church of Australia Queensland District (LCAQD) also raised the issue of the current funding of aged care services in rural and remote areas, and called for an aged care funding system that recognises the cost of providing aged care services in rural, regional and remote locations, where demand is smaller, and is often provided by not-for-profit organisations, it is more difficult to find and retain staff, workers may have to travel further and where access to specialist medical services and allied health clinicians is also challenging and not adequately supported by current funding.¹⁵⁸

Queensland PHNs submitted that current funding systems also prevent sustainable funding to allow pilot projects that demonstrate how care can be improved (such as by achieving greater health outcomes, reducing presentations to hospitals and reducing costs) to be replicated at scale and sustained. They stated 'Activity based funding in hospitals where the expertise lies and constant levels of funding without the clinical resources are barriers to evidence based care'.¹⁵⁹

¹⁵³ Submission 1229, p 6.

¹⁵⁴ Submission 1301, p 7.

¹⁵⁵ Submission 1283, attachment, p 2.

¹⁵⁶ Submission 1283, attachment, p 2.

¹⁵⁷ Submission 1281, p 6.

¹⁵⁸ Submission 1277, p 3.

¹⁵⁹ Submission 1301, p 7.

The Anglicare Australia Network called for a new residential aged care funding model based on relational care as an alternative to the consumer or transaction focus, stating:

*Relational care is fundamentally based on the elderly and staff alike having enough time for care to move beyond a mechanical list of physical requirements met...We need to reconceptualise the aged care system as a continuum of care model that meets community expectations, calibrated to Australia's demographic trends and accessible and equitable for all. At its core must be a commitment to responding to individual circumstances by partnering with older Australians in the design and management of the care they receive. This is not only a good design principle, but also reflects the right (and high expectations of an ageing baby boomer population) of people to make decisions about their own lives.*¹⁶⁰

4.2 Interface between the aged care system and public health systems

As mentioned above, the funding and regulation of aged care services is primarily the role of the Australian Government, with the state government providing assessment services as well as funding and/or delivering some residential aged care, home care and home support services.¹⁶¹

However, the care needs of older Australians require not just those services provided by the aged care sector, but also the health and human services sectors. The Australian Government provides the majority of funding for health and aged care services in Australia, however all three levels of government and the non-government sector are involved in the provision of these programs and resources.¹⁶² Of particular importance is the interface with the primary and acute health systems.¹⁶³

Both the Australian and state levels of government are involved in the provision of healthcare. The National Health Reform Agreement sets out roles and responsibilities for the Commonwealth and State levels of government in relation to providing health services. The table below sets out the roles and responsibilities under this agreement. Services accessed by older Australians in the health and aged care sector include those provided by medical practitioners, specialists, other health professionals, hospitals and clinics, respite and support services, transition services and community-based and residential aged care.¹⁶⁴ The states and territories also provide a range of health, housing and welfare services for the aged, often with joint Commonwealth funding, such as:

- respite care
- carer assistance
- home help
- dementia support programs
- transport assistance

¹⁶⁰ Submission 1229, p 6.

¹⁶¹ SCRGSP (Steering Committee for the Review of Government Service Provision) 2019, *Report on Government Services 2019*, Productivity Commission, Canberra, <https://www.pc.gov.au/research/ongoing/report-on-government-services>.

¹⁶² Australian Institute of Health and Welfare, *Older Australians at a glance*, 10 September 2018, www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/health-aged-careservice-use.

¹⁶³ Aged Care Workforce Strategy Taskforce, *A Matter of Care: Australia's Aged Care Workforce Strategy*, June 2018, p 1, https://agedcare.health.gov.au/sites/default/files/documents/09_2018/aged_care_workforce_strategy_report.pdf.

¹⁶⁴ Australian Institute of Health and Welfare, *Older Australians at a glance*, 10 September 2018, www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/health-aged-careservice-use.

- information services, and
- Seniors' Cards that allow discounts on a range of products and services.¹⁶⁵

Table 5: Roles and responsibilities of the Australian Government and Queensland Government for health service provision

Commonwealth	State
System management, policy and funding for GP and primary health care services	System management of public hospitals, including: <ul style="list-style-type: none"> • establishment of the legislative basis and governance arrangements of public hospital services, including the establishment of Local Hospital Networks (called Hospital and Health Services in Queensland) • system-wide public hospital service planning and performance • purchasing public hospital services and monitoring delivery of services purchased • planning, funding and delivering capital • planning, funding (with the Commonwealth) and delivering teaching, training and research • managing Hospital and Health Service performance • state-wide public hospital industrial relations functions, including negotiation of enterprise bargaining agreements and establishment of remuneration and employment terms and conditions to be adopted by Hospital and Health Services.
Establishing Primary Health Networks to promote coordinated GP and primary health care service delivery	Taking a lead role in managing public health
Working with each State and Territory on system-wide policy and state-wide planning for GP and primary health care	Sole relationship management with Hospital and Health Services to ensure a single point of accountability for public hospital performance, performance management and planning.
Promoting equitable and timely access to GP and primary health care services	
System management, planning, policy and funding, of the national aged care system.	

Source: <https://www.health.qld.gov.au/system-governance/health-system/managing/responsibilities>

Difficulties arise for older Australians when accessing such services due to the complexity of Australia's health and aged care systems. The funding of systems and the coordination of funding under different jurisdictions impact on the care given to older people. As stated by the Royal Commission:

*... funding and jurisdictional boundaries and professional silos can impact on access to care and the care experience for the older person and increase costs for older people and governments.*¹⁶⁶

¹⁶⁵ Parliament of Australia, Parliamentary Library, 'Caring for the Elderly' - an Overview of Aged Care Support and Services in Australia, E-Brief, 2003, https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/Publications_Archive/archive/agedcare.

¹⁶⁶ Royal Commission into Aged Care Quality and Safety, Navigating The Maze: An Overview Of Australia's Current Aged Care System, Background Paper 1, February 2019, p 15, <https://agedcare.royalcommission.gov.au/publications/Documents/background-paper-1.pdf>.

4.2.1 Strategies to improve the interface between aged care and health services

The Australian and Queensland governments have implemented a range of strategies to improve the interface between aged care and health care services. These strategies are outlined below.

4.2.1.1 Australian Government

The Australian Government has established primary health networks (PHNs) with the key objectives of:

*increasing the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and improving coordination of care to ensure patients receive the right care in the right place at the right time. PHNs aim to achieve these objectives by working directly with general practitioners, other primary health care providers, secondary care providers and hospitals to facilitate improved outcomes for patients. The Australian Government has agreed to seven key priorities for targeted work by PHNs, which includes aged care.*¹⁶⁷

4.2.1.2 Queensland Government

Nurse navigators

A recent Queensland Health initiative offers nurse navigators to help ensure patients' treatment is well managed across multiple providers. Although not specifically aimed at aged care, due to the increasing number of comorbidities seen in the older population, it is likely that a nurse navigator may become involved in helping to coordinate the care of older Queenslanders.

According to the Queensland Health website:

Nurse Navigators are a team of senior advanced practice registered nurses who provide a vital service for patients who have complex health conditions and require a high degree of comprehensive, clinical care.

Nurse navigators:

- *use a multi-disciplinary approach to monitor high needs patients, identify actions required to manage their health care and direct patients to the right service, at the right time and in the right place.*
- *provide a central point of communication and engagement to ensure optimal care and coordination of services along a patient's entire health care journey.*
- *educate and help patients to better understand their health conditions and enable them to self-manage, participate in decisions about their health care and improve their own health outcomes.*

*Nurse Navigators support and work across system boundaries and in close partnership with multiple health specialists and health service stakeholders to ensure patients receive the appropriate and timely care needed.*¹⁶⁸

Frail Older Persons program

As a means of addressing the increasing presentations to emergency departments and subsequent inpatient admissions of frail older people, Queensland Health developed the Frail Older Persons program. A core component of this program is the Residential Aged Care Facility Acute Care Support Services (RaSS) model of care. The following information was provided to the committee by Queensland Health:

¹⁶⁷ Australian Government, Department of Health, PHN Background, <https://www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Background>

¹⁶⁸ Queensland Health, Nurse Navigators, <https://www.health.qld.gov.au/ocnmo/nursing/nurse-navigators>.

The RaSS model of care currently operates in Cairns and Hinterland, Central Queensland, Gold Coast, Mackay, Sunshine Coast, Townsville and West Moreton Hospital and Health Services.

RaSS are Queensland Health funded services that aim to improve quality of care and choice of care setting for residents of Residential Aged Care Facilities with acute health care needs, that are beyond the scope of the general practitioner and Residential Aged Care Facility to manage independently of the hospital sector. The RaSS enable delivery of acute care in the Residential Aged Care Facility environment (where clinically appropriate and in keeping with resident wishes) through provision of emergency department substitutive care. RaSS provide:

- telephone triage – telephone assessment of acute care needs and matching the care need to the most appropriate care delivery service;*
- emergency department substitutive care – acute assessment or care in the Residential Aged Care Facility environment as an alternative to emergency department transfer, the types of care able to be delivered are determined by the scope of practice of individual RaSS staffing models;*
- geriatric nursing assessment for Residential Aged Care Facility residents presenting to emergency department or admitted to hospital;*
- discharge planning, co-ordination and transitional communication for Residential Aged Care Facility residents presenting to emergency department or with an acute admission, including for residents who have presented to and been discharged from emergency department after-hours; and*
- follow-up of all Residential Aged Care Facility residents via telephone consultation with Residential Aged Care Facility clinical nurses at 7 days (earlier if clinical need requires) to ensure fulfillment of referrals and resolution of care need.*

To support this model of care, Clinical Excellence Queensland has collaborated with general practitioners, Residential Aged Care Facility clinicians, consumers and specialists to develop a suite of care pathways specific to Residential Aged Care Facility residents to support Residential Aged Care Facility registered nurses and general practitioners in the early detection of deterioration and early institution of evidence-based care. These pathways also provide guidance as to appropriate referral pathways and specialist services that may be indicated in these particular clinical contexts.

...

In the event of acute deterioration, where resident care needs exceed the scope of the general practitioner to manage independently of the hospital sector, Residential Aged Care Facility residents may be referred by Residential Aged Care Facility clinical nurses, general practitioners or Queensland Ambulance Service paramedics to a RaSS. RaSS clinicians collaborate with residents or their substitute health decision makers, Residential Aged Care Facility registered nurses and general practitioners, to assess the acute healthcare needs of the resident and develop a comprehensive management plan. RaSS clinicians facilitate linkage to hospital specialist and community services (in-person, or via telehealth) to fulfil the resident's care needs in a manner consistent with the resident's goals of care.

...

Individual Hospital and Health Services determine the geographical catchment they are able to safely service, and limitations can include distance from the base site to the Residential Aged Care Facility and time of day. Residential Aged Care Facilities located distances to the base site may be offered modified services such as telehealth consultations, rather than face-to-face consultations.

*Improved care provided by the RaSS is supported by the Healthy ageing: A strategy for older Queenslanders, which focusses on helping Queenslanders to stay well in the community, to receive care closer to home and promoting seamless connection to health services.*¹⁶⁹

Additionally, Queensland Health has funded public private partnerships for startup costs for mobile x-ray services to provide mobile plain radiography services with radiologist reporting for Residential Aged Care Facility residents in Metro South and Metro North Hospital and Health Services.

Metro South Hospital and Health Services also facilitates specialist geriatrician telehealth consultations to rural areas that are without Geriatrician access, such as South West Hospital and Health Service.¹⁷⁰

4.2.1.3 Hospital and Health Services

As separate legal entities, with devolved responsibility and accountability for local service delivery, Hospital and Health Services determine the most appropriate care models for helping to prevent and minimise unnecessary hospital admissions for residents of aged care facilities.¹⁷¹ A summary of different initiatives is provided below.

Frail Collaborative (FRAIL)

FRAIL is a multisite collaborative project specifically designed to improve the flow of frail elderly patients through the health system, while also improving the clinical parameters of their care. The project is in development and will, when implemented, provide an evidence-based change package or 'bundle' for adoption by local teams. This bundle is being developed with the assistance of a multidisciplinary expert panel who have experience in geriatrics emergency and general medicine, along with patient safety and flow.

This collaborative will be limited to the emergency department presentation and inpatient admission elements, including the medical assessment/short-stay interface with emergency department and inpatient teams.

Benefits of the model of care according to Queensland Health include:

- focus on specific needs of the frail elderly in our hospitals
- fast-tracking care for frail elderly at point of arrival at emergency departments
- emphasis on listening to patients, families and carers
- development and sharing of innovative models of care
- improved emergency length of stay (ELOS) for 75+ age group, and
- reduction in avoidable admissions for 75+ cohort.¹⁷²

Comprehensive Aged Residents Emergency and Partners in Assessment Care and Treatment

Comprehensive Aged Residents Emergency and Partners in Assessment Care and Treatment (CARE-PACT) is a demand management program that focuses on streamlining and educating the care pathway for the frail elderly residents of aged care facilities. There are four main components to the model of care:

1. Telephone triage and clinical care planning that reduces avoidable emergency department presentations. Triage and care planning create a dedicated single point of contact for referral of deteriorating residential aged care facility patients. The referrals enable specialist emergency

¹⁶⁹ Queensland Health, correspondence dated 28 October 2019, attachment, pp 6-7.

¹⁷⁰ Queensland Health, correspondence dated 28 October 2019, attachment, pp 6-7.

¹⁷¹ Queensland Health, correspondence dated 9 April 2019, attachment, pp 5-8.

¹⁷² Queensland Health, correspondence dated 9 April 2019, attachment, p 5.

geriatric clinical assessment followed by appropriate linking of the patient to the most appropriate service to attend to their care needs.

2. An emergency department and inpatient resource and early discharge service. The resource and early discharge service maximise the opportunity for early discharge to the care of general practitioners, residential aged care facilities or acute care substitution services by facilitating integration of these services into the collaborative discharge planning process.
3. An emergency department equivalent assessment service in residential aged care facilities reduces avoidable emergency department presentations by reviewing patients with acute deterioration in the residential aged care facility, at general practitioner or Queensland Ambulance Services request, who would otherwise be sent to emergency departments across the district.
4. Where Queensland Health Hospital in the Home guidelines criteria have been met, CARE-PACT will provide inpatient hospital standard acute care substitution within the residential aged care facility.

Benefits of the model of care include:

- reduced emergency department presentations,
- reduced hospital admissions,
- reduction in iatrogenic complications,
- reduction in length of stay and inpatient admissions, and
- increased patient and carer satisfaction.

In 2017, Deloitte completed an independent evaluation of CARE-PACT as part of a broader evaluation of the Health Innovation Fund Round 1 Projects. The evaluation concluded that:

- The CARE-PACT project has proven to be successful in meeting its objectives of improving the quality of care for people living in residential aged care facilities (RACFs).
- Over the course of the pilot project phase, an estimated 1,522 ED presentation were avoided (valued at \$1.16 million), and an estimated 2,329 hospital admissions were avoided (valued at \$9.77 million).
- Over the course of the pilot project phase, the median LOS [length of stay] of admitted patients from RACFs was reduced by 1 day (valued \$3.83 million).¹⁷³

Older persons enablement and rehabilitation for complex health conditions (OPEN ARCH)

The Older Persons Enablement and Rehabilitation for Complex Health Conditions (OPEN ARCH) project team is formed via a partnership between the Cairns and Hinterland Hospital and Health Service, Torres and Cape Hospital and Health Service and the North Queensland Primary Health Network.

The model of care enables a direct path from general practitioners to community based geriatricians for comprehensive interdisciplinary assessment and care management. The model of care program is designed to facilitate timely access to the most appropriate care in the community that if provided early, could enable the older person's health to be supported such that they can remain living in the community and not require hospital attendance or admission.

General practitioners identify high risk consumers and refer to the specialist geriatric "hot clinic" for comprehensive assessment. Following specialist geriatric assessment, the client engages with an Enablement Officer whose role it will be to co-ordinate those recommendations made from assessment via referral to relevant existing primary healthcare services.

¹⁷³ Queensland Health, correspondence dated 9 April 2019, attachment, pp 5-6.

Benefits of this model of care include:

- specialist geriatric assessment care planning colocated with General Practice,
- reduction in emergency department presentations,
- reduction in hospital admissions, and
- reduction in in-patient bed days.¹⁷⁴

Geriatric Emergency Department Intervention

The Geriatric Emergency Department Intervention project has been developed to strengthen the capacity of the aged care sector to deliver high quality aged care, to improve care for older adults in emergency departments, and improve interaction between the residential aged care facility and primary and secondary healthcare sectors.

The project is provided by a nurse-led, physician championed team who provide frontload assessment, communication, care coordination and appropriate discharge planning. A Geriatric Emergency Department Intervention team focus on all presentations from aged care facilities as well as older people from the community who are identified as frail via screening on presentation to the emergency department.

Benefits of this model of care include:

- specialist assessment by geriatric emergency department nurse,
- reduced length of stay in emergency department for patients,
- fast tracking of patients through emergency department,
- improved emergency department discharge planning,
- updates on the patient's condition and progress can be provided to you on request, and
- improved communication between emergency departments and general practitioners.¹⁷⁵

The Residential Aged Care District Assessment and Referral

The Residential Aged Care District Assessment and Referral (RADAR) is a Nurse Navigator led service facilitating access to hospital-based and outreach services including:

- emergency department alternatives,
- facilitating hospital admissions,
- RACF resident post discharge medication review, and
- advice for navigating hospital services.

Currently within Metro North HHS, each hospital has developed its own services that provide inpatient and outpatient care to RACF patients. The RADAR Service provides one point of contact to facility-based residential outreach services.¹⁷⁶

4.2.1.4 e-Health initiatives

eHealth Queensland supports the information technology needs of Queensland's 16 Hospital and Health Services and the Department of Health. Although not specifically focused on aged care or older Queenslanders, these programs assist with improving access to health care information.

¹⁷⁴ Queensland Health, correspondence dated 9 April 2019, attachment, pp 6-7.

¹⁷⁵ Queensland Health, correspondence dated 9 April 2019, attachment, p 7.

¹⁷⁶ Queensland Health, correspondence dated 9 April 2019, attachment, p 8.

Integrated electronic medical record

Replacing paper-based clinical charts, the integrated electronic Medical Record (ieMR) allows healthcare professionals to simultaneously access and update patient information.

In June 2018, a PwC study of ieMR benefits showed \$181.9 million financial and economic benefits have been achieved across patient quality and safety, operational service improvement and direct financial savings at the Princess Alexandra, Mackay Base, Cairns, Townsville and Queensland Children's Hospitals.¹⁷⁷

The Viewer

The Viewer collates data from multiple Queensland Health systems, enabling healthcare professionals, including general practitioners, to access patients' information quickly without having to log in to different systems. The Viewer provides access to a range of patient information, including:

- Patient demographics, admission and discharge history
- Validated pathology results and tests ordered
- My Health Record
- Mental health data
- Problems and primary diagnosis from emergency departments and hospital admissions
- Discharge summaries
- Medication profiles and adverse reactions
- Operation notes and elective surgery waitlist information
- Radiology results
- Oncology information
- Alerts
- Endoscopy reports
- Advance Care Planning/Statement of Choices documents
- Acute management plans
- Clinical reports, and
- Medical images.¹⁷⁸

4.3 Issues with interface between federal and state aged care, health and human services sectors

The interface between federal and state government aged and health care services was consistently raised as an issue by submitters and hearing witnesses during the inquiry. The evidence provided to the committee indicated that older people receiving aged care services, particularly those in RACFs, suffer as a result of the fragmented interface between the aged care and health care systems, which sees disjointed service provision rather than continuity of care. The following provides a summary of those issues.

¹⁷⁷ Queensland Health, Integrated electronic medical record (ieMR), <https://www.health.qld.gov.au/clinical-practice/innovation/digital-health-initiatives/queensland/the-viewer>.

¹⁷⁸ Queensland Health, The Viewer, <https://www.health.qld.gov.au/clinical-practice/innovation/digital-health-initiatives/queensland/the-viewer>.

4.3.1 Interface between aged care and health services

The importance of the integration of aged and health care services can be seen in the summary provided by the Australian and New Zealand Society for Geriatric Medicine (ANZSGM) on the health risks experienced by older Queenslanders:

*...with increasing age comes an increased risk of a number of diseases associated with ageing, such as dementia, cancer, arthritis, osteoporosis, diabetes and other neurodegenerative diseases, as well as complex syndromes and clusters of conditions causing impairment such as frailty, reduced mobility and falls, delirium, incontinence and sarcopenia/weight loss. This is particularly so for those who live in residential care as they are more likely to be frail and/or experiencing cognitive impairment.*¹⁷⁹

The AMA Queensland expressed the following view, which reflects the view of many stakeholders to the inquiry:

*Increased cooperation is needed between residential aged care settings and/or aged care providers and service providers which deliver medical care, allied health care (e.g. physiotherapists, nutritionists, audiologists or occupational therapists), psychologists and geriatricians. This includes increased cooperation between RACF and the health system to ensure greater continuity of care for older Australians.*¹⁸⁰

Mr Francis Price, Director of Southern Cross Care similarly told the committee:

*If the intent of this committee is to make genuine recommendations around how to improve the provision of support for older people across Queensland, you can start by removing the barriers between state and Commonwealth that segregate responsibility for primary, acute and aged care, do nothing to improve the delivery and in many cases and circumstances result in negative outcomes and a significant waste of resources.*¹⁸¹

Some stakeholders identified the difficulties older people face when navigating health and aged care services provided or managed across jurisdictions as a key issue. For example, Catholic Health Australia advised that it regularly receives feedback that the current interface between residential aged care and the health sector is not working in the interests of people living in residential aged care.¹⁸²

SVHA referred to the impact on older people when required to deal with services funded and/or run by different levels of government:

*Australia's current aged care system offers a mix of different levels of Federal and State Government funding, eligibility rules and requirements. What this means in practice, is an individual is required to engage and coordinate at their time of need, appointments and documentation across a wide range of health and community-based providers over the primary health, acute care, human services, and aged care portfolios, all of which have differing administrative processes and requirements, as well as differing timeframes for approval of items, such as home care packages. The amount of "administrative work and coordination" that must occur across many agencies can be unnecessarily daunting and overwhelming.*¹⁸³

¹⁷⁹ Submission 1720, pp 3-4.

¹⁸⁰ Submission 1233, p 5.

¹⁸¹ Public hearing transcript, Brisbane, 4 July 2019, p 63.

¹⁸² Submission 1249, pp 2-3.

¹⁸³ Submission 1280, p 7.

COTA Queensland raised the issue of information breakdowns between different health and aged care providers:

Health care is provided in multiple settings and through a combination of state funding, federal funding and user-pays approaches. The interface between these settings and funding systems is frequently poor, particularly in an environment where an older person is likely to see multiple care providers for a variety of conditions and vulnerabilities. Information breakdowns may occur, for example, between GPs and hospitals, between specialists and GPs, between allied health providers and GPs, between community care providers and medical practitioners, and between residential-care providers and hospitals. While Nurse Navigators and My Health Record may help to alleviate some concerns in this area, more work needs to be done to develop a fully connected, integrated system.

...

*Improved integration between the health and aged care systems would enable greater continuity of care as well as a more efficient use of resources.*¹⁸⁴

Some submitters called for an improvement to the integration of the aged care and health care systems.¹⁸⁵ As summarised by the Brisbane South PHN:

*At a systems level, the federal and state governments need to interface seamlessly across the various health and human services departments involved in supporting older people and their carers/families. The interface between primary health care, hospital and specialist services (especially geriatric, psychiatric and psychogeriatric services) with organisations delivering home support, home care packages or residential aged care along with social services such as housing is essential but still has a long way to go and requires significant commitment and investment.*¹⁸⁶

Similarly, Palliative Care Queensland (PCQ) submitted that the development of integrated care models between primary and secondary care services/settings will greatly improve management of care, and therefore the older person's experience.¹⁸⁷ PCQ suggested the following key priorities for the Queensland Government in the delivery of aged care services:

- *Development of integrated care models*
- *Investment in integrated care (at state level)*
- *Collaboration between providers*
- *Collaboration and cooperation between governments.*

COTA Queensland advised that the AMA proposed that facilities need to improve the availability of experienced nurses and other health professionals, increase funding for medical practitioners to attend aged care facilities, improve access to palliative care services, improve access to mental health services, reduce polypharmacy, and improve access to specialist care.¹⁸⁸

However, the QNMU submitted that there is little opportunity, or incentive, to consider the broader system due to the state and federal separation of healthcare and aged care services, combined with a predominant public hospital system and a largely private, residential aged care system regulated at the federal level.¹⁸⁹

¹⁸⁴ Submission 1304, p 21.

¹⁸⁵ See, for example, submissions 1212, 1219, 1243, 1280, 1301, 1304, 1891.

¹⁸⁶ Submission 1212, p 2.

¹⁸⁷ Submission 1891, p 50.

¹⁸⁸ Submission 1304, p 17.

¹⁸⁹ Submission 1213, pp 19-20

Mr Ross Pitt agreed, submitting:

*...operational integration can only be achieved by close cooperation between funders (public and private) and levels of Government (State and Commonwealth). Currently there are no incentives for any provider to pursue this degree of integration.*¹⁹⁰

As well as calling for better integration across services, academics from the University of Queensland further suggested that the issue of whether health should be entirely under Commonwealth control should be revisited because of the 'inefficiency inherent in the state-Commonwealth split that currently exists'. They stated:

Many of the most vulnerable and needy suffer needlessly because of complexities of dealing with two parallel systems of health funding.

*For example, the Queensland government has removed state-run aged care beds, meaning residents are being financially supported through the aged care system. Their medical needs are supported through Medicare. Both are funded through the Commonwealth. However, when a patient needs specialist support, they are sent to state-funded Emergency Departments and hospitals. While this approach leads to various complexities and confusion for patients and their families, there are also case studies of patients being sent to emergency departments with minor ailments, to move the burden of funding to the other jurisdiction.*¹⁹¹

4.3.2 Interface between hospitals and RACFs

Despite the strategies to improve the interface listed earlier, a number of submitters raised issues in relation to the interface between hospitals and RACFs, and the impact this has on RACF residents. One of the main issues raised was the lack of continuity of care for residents when moving between RACFs and hospitals.

Aged and Disability Advocacy Australia (ADA Australia) put it simply when stating 'The current interface between residential care and health is not working. The quality of care is constantly being compromised by poor relationships between hospitals and aged care facilities'.¹⁹²

SVHA commented on the difficulties experienced by a resident when discharged from hospital:

*Referral and discharge between hospitals and aged care facilities requires the coordination of referral processes, sign off, form-completion, and approval from a multitude of health professionals across acute, sub-acute and primary health systems, and State and Federal agencies. Unsurprisingly, a person's experience of referral and discharge to and from a hospital or aged care facility is often less than satisfactory. Residents often become stuck, or are left stranded, in parts of the system which do not best suit their needs, waiting on one set of documentation to be completed or information to be approved for sharing between providers.*¹⁹³

...

*For example, the receiving aged care facility is often not provided with the appropriate notice of discharge, nor the relevant information by the hospital about an incoming resident. What this means is that important health information about the resident is not available to staff at the facility and this can result in readmission of the client back to hospital.*¹⁹⁴

SVHA advised it is important to see the transition of an elderly person from hospital into aged care as involving the same spectrum of care, and commented that 'An individual in this position is less likely

¹⁹⁰ Submission 471, p 2.

¹⁹¹ Submission 1219, p 5, 6.

¹⁹² Submission 1243, p 5.

¹⁹³ Submission 1280, p 10.

¹⁹⁴ Submission 1280, pp 7-8.

to be worried about which level of Government “pays for what” and just wants a continuity of good quality care and access to support so their quality of life is maintained with dignity and respect’.¹⁹⁵

The cost to the state government and the impact on the state health system of an older person staying in hospital rather than being cared for at their RACF was also raised as an issue by stakeholders.

For example, SVHA submitted that there is a substantial cost to Queensland’s public health system if elderly persons are left waiting in hospital wards while a suitable aged care place is found for them.¹⁹⁶

PCQ identified several costs associated with an extended length of stay in an acute facility, including:

- the additional costs per bed day – an acute hospital bed costs approximately \$1000-\$1500 per day, depending on the hospital, and
- the occupation of an acute hospital bed with a non-acute patient reduces activity and productivity of the acute hospital.¹⁹⁷

Both Churches of Christ and Mr Ross Pitt raised the issue of acute beds being filled by people who are ready to be transferred to a RACF, making the beds unavailable for others.¹⁹⁸

Mr Pitt submitted:

*Keeping a focus on aged care, end-of-life care and palliative care as a triad of interrelated activities within the health care system is essential. This broader focus is still not happening operationally or funding wise. The cost of the existing silo mentality for residents/patients is the poorly coordinated, even chaotic, service provision universally experienced by patients/residents and carers. The cost of the existing silo mentality for the health system is an unacceptably high level of “bed blockers” in the acute care system which, on any one day, is the equivalent to three standard sized nursing homes in Brisbane alone. The problem is the same in the public, private, and not-for-profit sectors, and (depending upon how you define a “bed blocker”) accounts for well over 10% of bed occupancy across the entire acute care system in Queensland.*¹⁹⁹

Southern Cross Care (Qld) observed that the demands experienced in the Commonwealth funded aged care and the state funded health systems are interrelated, submitting ‘A lack of available residential aged care beds and long waiting lists for homecare packages places demand on Queensland Government services to meet needs the Commonwealth should be meeting’.²⁰⁰

However Southern Cross Care (Qld) also noted that RACF residents are as entitled to Queensland Government health services as other citizens, rather than the perception being that RACFs should be a sub-acute health care facility.²⁰¹

On the matter of providing health care to residents, there was disagreement on the role of an RACF in providing that care. Catholic Health Australia submitted that aged care homes are not self-contained health services, stating:

*In order for residents to receive timely access to medical services, they are heavily reliant on the wider health care system. As for any Australian living in the community, aged care residents should have timely access to medical services when needed.*²⁰²

¹⁹⁵ Submission 1280, p 12.

¹⁹⁶ Submission 1280, pp 15-16.

¹⁹⁷ Submission 1891, p 49.

¹⁹⁸ Submissions 1281, p 7; 471, p 1.

¹⁹⁹ Submission 471, p 1.

²⁰⁰ Submission 1245, attachment, p 2.

²⁰¹ Submission 1245, attachment, p 2.

²⁰² Submission 1249, pp 2-3.

Similarly, the Queensland Law Society (QLS) advised:

*RACFs are not hospitals, and too often there is a conflation between the promised or expected services, and realistic outcomes regarding provision of services. Further, a perception exists, and is reported to our members by RACFs, patients and their support persons, that RACFs should not send residents to hospital for medical care and attention. It should be recognised that RACFs are accommodation with some services added, they are not fully equipped hospitals which provide some social and residential activities.*²⁰³

In contrast, the QNMU argued RACFs should be considered health care services, stating:

Their appears to be a widespread view aged care, particularly residential care, is not health care despite the significant, and increasing, health care needs of residents. The QNMU believes all residential aged care services should be classified as health services, irrespective of how else they are categorised. This lack of acknowledgement of aged care as a health service means aged care providers have little incentive to invest in hospital avoidance processes such as primary care and on-site clinical (nursing, medical and allied health) interventions.

...

*...there must be timely and adequate access to medical, allied health and social care support to meet the aims of the resident's individual care plan. This could be achieved through better integration with primary health networks, hospitals and outreach services.*²⁰⁴

Some submitters also referred to the detrimental impact hospital stays can have on older people.

Professor Marianne Wallis told the committee:

*Hospitals can actually be dangerous places for frail older people. There are lots of lights and buzzers and noise and it is a difficult technical environment. People can become more confused, can injure themselves and can develop more complications.*²⁰⁵

Queensland PHNs referred to substantial evidence that hospitalisation is detrimental to frail elderly people, stating 'In addition to the economic costs of the hospital bed versus residential care costs, the individual has poor health outcomes'.²⁰⁶

PCQ also referred to studies that have pointed to detrimental impacts that prolonged hospitalisations have on older people such as iatrogenic illnesses (e.g. infection), cognitive and functional decline.²⁰⁷

Churches of Christ questioned the availability of suitably educated staff in the acute sector to care for elderly people, in particular with cognitive impairment. They indicated a lack of such staff '...frequently results in poor care outcomes. Increased incidence of Delirium'.²⁰⁸

The QNMU submitted that avoidable hospitalisation of aged care residents has the potential to cause unnecessary harm and distress and should therefore be regarded as a potentially abusive practice.²⁰⁹

Conversely, continuity of care and the impact on the older person and on the health system of patients being released from hospital too soon was also raised, and particularly the ability for RACFs to care for a resident upon discharge.

²⁰³ Submission 1201, p 3.

²⁰⁴ Submission 1213, pp 19-20.

²⁰⁵ Public hearing transcript, Caloundra, 3 May 2019, p 3.

²⁰⁶ Submission 1301, p 7.

²⁰⁷ Submission 1891, p 49.

²⁰⁸ Submission 1281, p 7.

²⁰⁹ Submission 1213, pp 19-20.

ADA Australia submitted that because RACFs are not stand-alone health services, they don't always have the appropriate expertise onsite to identify changes in care requirements following hospital discharge.²¹⁰

The LCAQD suggested that Australian hospitals have reduced their length of stay for 'planned and unplanned activity', and as a result:

some residents require additional "post-acute" care in addition to their routine care in the form of post-operative wound management, restorative care or dedicated rehabilitation.

In our review of clinical incidents, we have observed that some residents who were in-patients have been discharged back into our care with very complex post-acute care wound management and other post-acute intervention requirements. In some cases, this brings into question the initial discharge decision by hospital. We see benefit of a community-based visiting specialist to oversee wound management for residents post-hospitalisation and for those with complex care needs post-discharge (such as stomas or amputations).²¹¹

The QLS also commented that any rehabilitation which is given will usually become the responsibility of personal care workers, who are not likely to be appropriately qualified in the provision of the designated therapy.²¹²

Queensland PHNs raised concerns that many people accessing state funded services on discharge from hospital are missing out on services, or receiving services for a shorter duration than is within the program guidelines due to competing demand for services. Queensland PHNs stated 'There remains ongoing misalignment with My Aged Care and older people receiving support services as a timely response'.²¹³

Both Woombye Care and the QNMU commented that RACF residents receive a higher level of care in hospital than they do in their RACF. Woombye Care advised that while this means there is a significant cost to the health system, residents can be pushed into aged care facilities from hospital too soon and before they are actually clinically stable for discharge. Because the maximum funding that aged care facilities are given for a resident is much less than what governments allow for a patient in hospital, this can end up being more a burden on the health system as the resident may require a re-admission to hospital.²¹⁴

QNMU expressed concern at the disparity in care between the hospital and aged care sectors, and stated:

The disparity in levels of care and increasing waiting times for placement simply highlight the need to overhaul the current system and point to the need for greater integration between the hospital, health and aged care systems.²¹⁵

Some stakeholders suggested that the reasons for the movement of older people between RACFs and hospital was due to funding models or a lack of adequate care in facilities. For example, National Seniors Australia stated:

The current funding model for health and aged care results in circumstances in which residents in aged care facilities end up in the hospital system. A lack of access to primary health care and palliative care services within residential care settings, for example, means that aged care

²¹⁰ Submission 1243, p 5.

²¹¹ Submission 1277, p 5.

²¹² Submission 1201, p 3.

²¹³ Submission 1301, p 2.

²¹⁴ Submission 1254, p 2.

²¹⁵ Submission 1213, pp 19-20.

*residents are often sent to emergency departments and are admitted to hospital adding a significant cost burden to the health system. Unfortunately, the disparate and disjointed funding models for health and aged care exacerbate this situation because it encourages cost shifting between aged care and hospital settings.*²¹⁶

Dr Will Cairns told the committee that ‘the distribution between the states and the commonwealth of responsibility for the funding of the various components of healthcare means that there are incentives to game patient care so that it is funded by someone else’.²¹⁷

Southern Cross Care (Qld) advised it believes that the current divided responsibilities between Commonwealth and State jurisdictions ‘...along with sometimes counter-productive funding motivations leads to service delivery for elderly people that does not serve theirs or the community’s interests and often leads to more expensive care outcomes’. Southern Cross Care (Qld) called for inter-jurisdictional alignment that prioritises policy, funding and localised service delivery coordination, stating ‘...whilst cost and blame shifting remain a challenge for the Federation, an increase in the number of older people and their entitlement to best coordinate services underscores this imperative’.²¹⁸

4.3.3 Access to General Practitioners, specialist medical staff and allied health professionals in residential aged care

Difficulties accessing GPs, specialist medical staff and allied health professionals, particularly for residents of RACFs, was raised as a significant issue, with stakeholders calling for the same equity of access to health services as people in the community.

Palliative Care Queensland (PCQ) stated that the aged care sector reforms started in 1997 have meant more autonomy for older people but reduced access to nursing and other health services, including access to general practitioner and palliative care services.²¹⁹ Access to palliative care is discussed further at section 7.8.6.

Dr Neisha D’Silva referred to the difficulties older people can have accessing the health care they need either at home or in an RACF:

*Frail, older Australians with multi-morbidity and receiving either coordinated care at home or living within residential care homes are among the most complex the health system has to manage and yet it can be difficult for these people to access the specialist interdisciplinary care that they so desperately need. The complex interaction of medical, psychosocial, physical and cognitive needs requires the care of person centred teams that are expert in that degree of complexity and should include Geriatricians. This needs to occur throughout the journey across the care continuum from the initial interface with assessment teams such as the Regional Assessment Service (RAS) and Aged Care Assessment Team/Service (ACAT/ACAS), through community service provision, into and out of acute and subacute hospital and health services and through to residential care and eventually end of life care. No older person in Australia should have to access increased support or enter residential care for want of the management of a potentially treatable condition.*²²⁰

Queensland PHNs contended that the care system has not responded well to the complex health care needs of people who are entering residential aged care at an older age than previously, with higher

²¹⁶ Submission 1309, p 5.

²¹⁷ Submission 1940, p 15.

²¹⁸ Submission 1245, attachment, p 2.

²¹⁹ Submission 1891, p 39.

²²⁰ Submission E1882.

care complexities and for shorter periods of time prior to death.²²¹ Queensland PHNs also submitted that many RACFs continue to use outdated models of care that do not meet current consumer expectations, and referred to Queensland Ambulance Service (QAS) reports regarding lack of after-hours medical advice for palliative care patients which result in QAS having to 'inappropriately' transport the patient to HHS emergency department.²²²

Churches of Christ commented that gaps in healthcare access for residents in residential aged care are significantly greater than for people in the broader community, particularly for services such as dental care, mobile X-ray, hospital outreach for complex care such as in-dwelling catheter, complex wounds and IV antibiotics, post hospital sub-acute support and psychogeriatric care.²²³

The AMA Queensland similarly submitted that it believes timely access to appropriately trained staff in multidisciplinary teams is becoming increasingly difficult, particularly registered nurses and allied health, which it stated are essential when it involves the care of patients with chronic disease conditions.²²⁴ AMA Queensland advised it believes:

*the mix of staff in different settings should correspond with the care needs of residents but this is not what currently happens in the majority of settings with access to registered nurses, allied health and psychologists becoming increasingly difficult. Of particular concern is the rapid increase in the number of personal care workers whose training (Certificate 3 or 4) is insufficient to care for older people in RACS, many of which have complex conditions.*²²⁵

SVHA advised it can be difficult to access external complementary health and other services to support the existing staff skill mix, particularly in regional, rural and remote settings. SVHA advised the following factors can impact on the mix of staff in the aged care sector:

- poor access to local GPs (especially in regional/remote areas), particularly GPs who specialise in aged care
- waiting lists for geriatric specialists are extensive. Specialists do not always conduct service visits which is a challenge for residents and facilities, as well as for their families who often must take them to appointments
- the current funding model does not afford aged care facilities with the opportunity to staff services with more registered nurses, nurse practitioners, allied health, counselling and social work professionals.²²⁶

A number of stakeholders called for better access to GPs for those in RACFs.²²⁷ For example, ADA Australia submitted:

Access to general practitioners (GPs) is an issue often raised in advocacy case work. Clients residing in residential aged care often report that GPs do not visit frequently enough, spend as little as 5 minutes with each resident and are often strongly influenced by the aged care facilities that contract them. Although, aged care residents have the right to access the GP of their choice, there is a very limited supply of GPs willing to conduct visits in residential aged care facilities.

²²¹ Submission 1301, p 3.

²²² Submission 1301, p 3, 6.

²²³ Submission 1281, p 8.

²²⁴ Submission 1233, p 2.

²²⁵ Submission 1233, p 3.

²²⁶ Submission 1280, pp 14-15.

²²⁷ See, for example, submissions 1212, 1213, 1279, 2052.

*ADA Australia believes further incentives are required to encourage GPs to engage with patients in the residential aged care setting.*²²⁸

Brisbane South PHN similarly submitted that continuity of GP care should be encouraged (through funding and other mechanisms) and monitored, and that qualified nursing personnel in the RACF is an essential component to support GP care.²²⁹

Stakeholders also commented on the limited access RACF residents have to allied health services and other specialist health services, such as dental care and mental health support, and called for better access to such services.²³⁰

As an example, the Australian Association of Social Workers (AASW) Qld Branch advised that the current model of aged care is missing an equal focus on the psychosocial needs of the person as it has on the physical needs of the person, submitting:

*Social workers provide essential services to meet people's psychosocial needs and enable older people and their families to access the aged care system, particularly at the interface between health and aged care. Yet despite being a key allied health service, social work is often missing in services for older people outside of hospitals and particularly in residential aged care.*²³¹

The RANZCP similarly raised the issue of poor access to specialised care for people with intellectual and developmental disorders, mental illness and neurodegenerative disorders (e.g. dementia, Alzheimer's).²³²

However, it's not only conditions that may be pre-existing or related to ageing that may need to be addressed by health care workers. The Australian Association of Social Workers (AASW) advised that older people often experience grief and loss, depression and anxiety when entering residential aged care facilities. This arises through the loss of their home, separation from loved ones (quite often their spouse) and loss of access to their community. AASW state that research has shown:

- *Over half of all permanent aged care residents had symptoms of depression;*
- *Just under half of people entering residential aged care for the first time had symptoms of depression; and*
- *Residents with symptoms of depression had higher care needs.*²³³

To improve the health and mental health services provided within RACFs, the RANZCP stated there is a need to:

- increase patient access to general practitioners (GPs) and allied health professionals
- increase the numbers of registered nurses
- provide access to multidisciplinary teams
- increase RACF and health staff to patient ratio

²²⁸ Submission 1243, p 5.

²²⁹ Submission 1212, p 4.

²³⁰ See, for example, submissions 1207, 1243, 1279, 1288, 2052.

²³¹ Submission 1288, p 5.

²³² Submission 1207, attachment, p 3.

²³³ Submission 1288, p 6; Australian Institute of Health and Welfare 2013. Depression in residential aged care 2008–2012. Aged care statistics series No. 39. Cat. no. AGE 73. Canberra: AIHW, <https://www.aihw.gov.au/getmedia/7ad35fb2-bc14-4692-96b1-c15d73072319/16256.pdf.aspx?inline=true>.

- improve training and education of RACF and health staff, particularly in dealing with behavioural management, dementia, and mental health issues
- improve access to specialist mental health care
- introduce mechanisms to manage the over prescription of psychotropic drugs to people in RACFs, and
- improve communication between RACFs and acute mental health units (which older people are sent to when exhibiting behavioural disturbances).²³⁴

To ensure older Queenslanders residing in residential aged care have the right to access the same suite of health services and programs available to the broader community, Queensland PHNs submitted:

*There needs to be an adequate number and mix of personal carers, enrolled nurses, registered nurses, clinical nurse practitioners, allied health and visiting medical officers including general practitioners with timely access to geriatricians, psychiatrists and other medical specialties.*²³⁵

4.3.3.1 Funding and the Medicare Benefits Scheme

Many stakeholders commented on the inadequate level of funding available to ensure equity of access for older people to health services, particularly for residents of RACFs.

Dr Will Cairns advised the committee that current funding models can be a disincentive for doctors, and in particular GPs, to provide the care that is necessary for people who are now living into old age with multiple serious co-morbidities.²³⁶

The LCAQD similarly submitted that the current funding incentives for GP consultation and multidisciplinary team leadership at key points of clinical care - such as discharge planning, rapid clinical deterioration, palliative care planning and planning care for residents with cognitive decline - impact negatively and increase pressure on clinical teams to provide care for residents at these times. The LCAQD advised that the current incentives do not allow for consultation of a protracted and complex nature, and also noted the difference between funding for palliative care in a RACF and in hospital.²³⁷

In relation to GPs, the AMA Queensland commented that the current remuneration arrangements under the Medicare Benefits Scheme (MBS) limits the involvement of General Practitioners in RACFs. AMA Queensland provided the following explanation:

Item numbers under the MBS describe an episode of care, have a number of components and often a minimum time period as well as a descriptor to other item numbers which may be relevant.

In the normal course of events, when someone comes to see a General Practitioner an item number will be charged. If its bulk-billed, then a payment will be charged to Medicare or if there's a shared payment facility then a payment will be made by the patient and Medicare will pay the balance. Standard consults are level B \$37.60 or for consults which require more complex consultation level C.

However, in a residential aged care facility the payment depends on the number of patients seen in the facility at the one time. So if one patient is seen the rebate is \$85.00 then if two patients are seen, the rebate which can be accessed is \$37.60 so the two rebates are combined and

²³⁴ Submission 1207, attachment, pp 4-5.

²³⁵ Submission 1301, p 6.

²³⁶ Submission 1940, p 15.

²³⁷ Submission 1277, p 5.

divided by two. The third patient accessed the rebate is \$37.60 combine the three rebates together and divide by three and so on up to six.

By the time the General Practitioner see's the seventh patient the rebate will be \$40.95. The AMA suggests this level of compensation for a General Practitioner to see a patient in a residential care facility is inadequate, particularly as the recompense bears no resemblance to the cost of providing that care. A recent survey of members of the AMA indicated that anywhere between a 50 to 100 percent increase in the Medicare rebate was appropriate to compensate for the care.

Aged and Community Care Australia recently admitted that aged care providers can't guarantee that a General Practitioner will actually visit a patient in an aged care residential facility, and because facilities don't generally employ General Practitioners on staff, then it is becoming increasingly rare that a resident can go and visit a General Practitioner in that setting.²³⁸

COTA Queensland also stated that for residents in aged care, access to a GP can be an issue, submitting:

The 2017 AMA Aged Care Survey showed that GPs often discontinue visits to residential facilities because unpaid non-face-to-face time increases, their practices are too busy, the patient rebate is inadequate and the patient rebate doesn't compensate for time lost in the surgery.²³⁹

From an RACF provider's perspective, Churches of Christ advised that access to GPs for RACF residents continues to represent a challenge and is anticipated to increase with GPs opting not to provide services to people in this setting. Churches of Christ suggested that nurse practitioners provide a potential alternative to some of this GP care, if they can be educated and attracted to the sector.²⁴⁰

Professor Marianne Wallis also stated that, because a GP's business model means that clinic based care is the best and most efficient way for them to deliver care, a better model of care may involve a GP liaising with someone on site who could prescribe certain things and who could order tests, thereby reducing their need to visit but still providing coordinated care.²⁴¹

PCQ called for the Australian Government to review the MBS item numbers regarding care for older people in RACFs and in the community.²⁴²

The issue of funding for allied health care services was also raised by stakeholders. Woombye Care observed that in certain circumstances it is up to the facility to pay for extra allied health services such as podiatry, physiotherapy, speech pathology, all of which can be expensive thus preventing the access to these services.²⁴³

Mr John Redman similarly commented that funding for services such as physiotherapy is insufficient, and affects access to these services.²⁴⁴

Churches of Christ commented that there are currently shortages of allied health professionals looking to work in aged care, particular physiotherapists, due largely in part to the 'current funding model which does not reward re-ablement and evidence based practices'.²⁴⁵

²³⁸ Submission 1233, p 4.

²³⁹ Submission 1304, p 17.

²⁴⁰ Submission 1281, p 6.

²⁴¹ Public hearing transcript, Caloundra, 3 May 2019, p 13.

²⁴² Submission 1891, p 51.

²⁴³ Submission 1254, p 2.

²⁴⁴ Submission 2557, p 3.

²⁴⁵ Submission 1281, p 6.

The LCAQD stated that case conferencing including allied health, psychology services and specialist nursing services would be better supported with access to specifically itemised funding for the participation of these clinicians.²⁴⁶

ACSA argued that aged care providers are not adequately funded to provide the palliative care required by residents of facilities, referring to the number of facilities making a loss as a result of funding provided and the services they are expected to provide to make their point.²⁴⁷ The lack of adequate palliative care funding to residential and community aged care providers has resulted in the lack of:

- sufficiently skilled palliative staff.
- the availability of palliative care equipment and resources.
- access to palliative care specialists.²⁴⁸

ACSA also stated that aged care providers report that access to palliative care advice and support services are limited.²⁴⁹ ACSA called for increased funding to increase the capacity of the aged care workforce to support adequate aged care staffing and specialist palliative care services to manage the holistic requirements and fluctuating palliative clinical and emotional needs of an older person approaching end of life is required.²⁵⁰

The QNMU submitted that, because those receiving aged care services, particularly residential aged care, require significant levels of health care due to multiple diagnoses, comorbidities, polypharmacy, debility, cognitive decline and frailty, RACFs must be identified and regulated as health services and should be subject to the same health service and clinical standards as are other health services such as hospitals. The QNMU stated:

The QNMU believes the same health care standards must apply irrespective of setting with the appropriate human and material resources required to provide that care safely and to a high standard.

In particular, the long-term decline in regulated aged care nurse numbers who lead the assessing, planning, delivery and monitoring of care, particularly complex care, has had a negative impact on the safety and quality of that care. This lack of clinical capacity is also reflected in unnecessary transfers to emergency departments with the resulting disruption, cost shifting and use of acute resources that results.

A particular area the QNMU believes should be addressed as a matter of urgency relates to the capacity of aged care facilities to provide appropriate primary care services and facilities on site. According to the Queensland Health Minister, over 25,000 aged care residents were transported to emergency departments in the period in FY2016-17, a 17% increase in the past year (Bita, 2018). For example, the for-profit provider Regis has been identified in the media as a provider which, it is alleged, has a low threshold for transferring residents to emergency departments (Morton, 2018).

An increase of 25% in emergency department transfers from aged care facilities has also been reported in Victoria (Bachelard, 2017). According to the Australian Medical Association (2018), in one review, a third of presentations of residents to emergency departments who subsequently returned to their facility could have been avoided by incorporating primary care services at the facility level. Such services include both the physical infrastructure and the skilled staff needed,

²⁴⁶ Submission 1277, p 5.

²⁴⁷ Submission 1285, p 4.

²⁴⁸ Submission 1285, p 6.

²⁴⁹ Submission 1285, p 5.

²⁵⁰ Submission 1285, p 6.

*e.g. RNs and general practitioners. Again, the capacity of aged care facilities to provide primary care and to practice hospital avoidance has been significantly impacted though systemic deskilling of the aged care workforce and a model of care that deemphasises the clinical aspects of residential aged care.*²⁵¹

4.3.4 Opportunities for the Queensland Government to take a lead role to improve aged care

Stakeholders identified a number of opportunities for Queensland Government to improve the interface between federal and state aged care, health and human services sectors. These opportunities include improved communication, collaboration and information sharing. Stakeholders also expressed support for programs implemented by the Queensland Government or individual HHSs to improve the interface between services.

4.3.4.1 Support for Care-PACT

In their submission, PCQ referred to the CARE-PACT model outlined in section 4.2.1 as an example of an innovative, integrated model that can create savings for the Queensland Government, increase the quality of care for frail older people and reduce the demand placed on the hospital sector.²⁵² They also referred to a recent expansion to CARE-PACT which saw the implementation of a chronic wound service, mobile x-ray service, nurse navigator mediated case management and a Nurse-Practitioner position which allows the treatment of older patients in the familiar surrounds of their own environment. PCQ suggested that further development of clinical pathways will improve implementation of an evidence-based approach in the emergency department.²⁵³

4.3.4.2 Support for nurse navigators

The nurse navigator and nurse practitioner models were identified by stakeholders as potentially beneficial for improving the quality of care given to older Queenslanders as well as providing financial benefits for the Queensland Government and health practitioners. For example, COTA Queensland called on the Queensland Government to ensure that all HHS regions have sufficient Nurse Navigators to service the needs of older Queensland and to ensure they have experience in geriatric and palliative care.²⁵⁴ The SVHA also supported trialling models ‘such as “hospital in the aged care facility” or increasing the number of nurse practitioners working in the aged care sector and affording them the opportunity to access MBS items’.²⁵⁵

The QNMU advocated for the nurse practitioner model, and referred to a range of positive outcomes identified through research, which included:

- *improved access to primary care for older people though filling service gaps and supplementing general practitioner services;*
- *the provision of new and expanded services and the development of innovative delivery models;*
- *a range of models across sub-acute care, primary care and primary health;*
- *reduction in unnecessary hospitalisations;*
- *education and skill development for the aged care workforce;*

²⁵¹ Submission 1213, pp 21-22.

²⁵² Submission 1891, p 50.

²⁵³ Submission 1891, p 50.

²⁵⁴ Submission 1304, p 19.

²⁵⁵ Submission 1280, p 18.

- *coordination of care.*²⁵⁶

Professor Marianne Wallis advised the committee that research on the nurse practitioner model found:

*...that there were savings to the health service from a reduction in presentations; there were savings to GPs because the GPs did not have to leave their clinics and travel to the aged-care facility—they could liaise with the nurse practitioner candidate; and there were lots of savings to the Ambulance Service, but there were no savings to the residential aged-care facility. There is this interesting shift where the residential aged-care facility is paying for the service; they are seeing an improved quality of care, but the cost savings are to the other side of the equation.*²⁵⁷

4.3.4.3 Better communications and access to electronic patient records

In its submission, ADA Australia commented on the need for improved communication between hospitals and RACFs to assist with continuity of care and better health outcomes for older Queenslanders. Their submission commented in particular on the importance of the transitional stages when older people are entering or exiting hospital, and during hospital discharge.²⁵⁸ ADA Australia stated:

*Residential care facilities require direct communication about important discharge information including details on changes to a resident's circumstances and medication and direction on how care plans should be updated.*²⁵⁹

The SVHA similarly submitted that the Queensland Government needs to address the poor communication between hospital and aged care facilities, stating this poor communication 'is often reflected in the way hospitals discharge aged care residents, a process that often involves little or no consultation with the aged care providers'. In their submission SVHA recommended the improved use of technology, particularly for discharge from hospital, providing the following example:

*...we believe better technology could help with tracking a resident's appropriate medication upon discharge. Currently, a hospital's poorly managed discharge of an elderly person to an aged care facility – without the appropriate details around their ongoing medication – can result in up to two days wait as the regular GP has to review the prescription first and provide clearance.*²⁶⁰

Stakeholders also raised the use of technology to improve the integration of services, particularly the ability to share medical records.

In their submission PCQ referred to the implementation of the integrated electronic Medical Record (ieMR) across Queensland Health facilities and services, suggesting it will be critical for integrated care models. In their submission PCQ also referred to the emergence of virtual health models to help manage the medical and care needs of older people in their own home, rather than in the acute care setting, stating 'This is particularly important for older people living in outer regional, remote and very remote areas of Queensland'. PCQ acknowledged that there may be difficulties with sharing information across organisations and different platforms, but suggested these barriers should not be insurmountable.²⁶¹

The SVHA proposed the sharing of access to electronic medical management systems (EMSs):

²⁵⁶ Submission 1213, p 21.

²⁵⁷ Public hearing transcript, Caloundra, 3 May 2019, p 3.

²⁵⁸ Submission 1243, p 5.

²⁵⁹ Submission 1243, p 5.

²⁶⁰ Submission 1280, p 15.

²⁶¹ Submission 1891, p 51.

*EMS in the future could better support discharge and health care planning between hospitals, GPs and aged care facilities to help improve coordination of information and care across different agencies.*²⁶²

The submission from AMA Queensland commented on the inability of GPs to access a resident's aged care records. They advised that it was another factor that limits the quality of care a GP can provide to residents of RACFs, submitting:

One of the most important issues for General Practitioner is the level of access to the patients aged care records, and this becomes particularly difficult when the residential aged care facilities clinical records are not compatible with the General Practitioners own data systems.

Access to this information is one of the most important issues associated with providing continuity of care, which relates to the General Practitioner having a clinical history and connection with the patient. This is less of an issue when the patient being seen in a facility has been part of the General Practitioners practice, as often knowing what concerns him or her and the values that go into their care are an important part of the trust and relationship between General Practitioner and patient.

*It is more of an issue when a General Practitioner sees a patient for the first time in a residential aged care facility. The patient may already be stressed, have anxiety and the worry of being in a facility and then have to discuss their health with a General Practitioner who they may not know. General Practitioners being able to access a patient's records prior to this first appointment and the General Practitioner having a thorough understanding of their health conditions may help alleviate this worry.*²⁶³

Further to these points, AMA Queensland called for GPs to receive a copy of the medical report from the emergency department of hospitals at the time the patient is discharged from hospital back to the RACF to ensure continuity of care of the patient.²⁶⁴

The QNMU suggested that technology could be used to better track the care being provided to RACF residents, submitting:

enhanced data collection regarding transfer of residents to hospital from residential aged care facilities has the potential to inform how well a provider is meeting the needs of residents. Improving the quality of coroner's data for deaths in the residential setting should also be considered as a mechanism for understanding outcomes such as premature death in the aged care setting (Ibrahim, 2017).

The QNMU proposed that the degree of integration with the broader health system should be part of the requirement for accreditation under the national scheme.²⁶⁵

4.3.4.4 Digital prescriptions

The Pharmacy Guild of Australia referred to the administrative burden faced by GPs and pharmacists doing work two to three times on multiple systems to service the one patient, stating:

Faced with increasing funding restraints, GP's and pharmacists are finding it more and more challenging to service RACFs. The options for RNs to record administration of medications are also many and varied. The Guild's recommendation is that it should be compulsory for the supply of medication in RACFs to be via the use of a standard document either an NRMCM or more ideally a digital prescribing platform. A single digital platform for all medication related matters in an RACF

²⁶² Submission 1280, pp 15-16.

²⁶³ Submission 1233, p 4.

²⁶⁴ Submission 1233, p 5.

²⁶⁵ Submission 1213, p 21.

*would provide efficiencies that would enable all professionals in the medication continuum to better utilise their skills to improve patient outcomes.*²⁶⁶

4.3.4.5 Better advocacy for older Queenslanders

The QNMU also proposed that the Queensland Government could drive improvements in aged care delivery via advocacy for older Queenslanders, given that ‘because aged care largely falls under federal jurisdiction, the capacity for state governments to act in this area is seen as limited, and untested’. The QNMU suggested the following possible approaches:

- *In conjunction with the States and Territories, the Commonwealth fund an Aged Care Ombudsman/Commissioner Office to assist consumers of aged care as they encounter issues in dealing with this complex system. It is anticipated that this Ombudsman/Commissioner role would work in a co-regulatory capacity with the Aged Care Quality and Safety Commission in a similar way to existing coregulatory models in other parts of the health care system, e.g. the Queensland Office of the Health Ombudsman. A state based approach is suggested as this brings the function closer to those who would use the system and acknowledges that each state and territory jurisdiction has its own idiosyncrasies;*
- *Funding for advocacy services must be increased. Again, the experience of the QNMU is that significant advocacy resources are required to assist older Australians to effectively utilise the aged care system, and while advocacy organisations working in this space are highly effective, they do have capacity and funding constraints such that people do still fall through the cracks. Failure to fund advocacy services to assist those using the aged care system is simply false economy which leads to poor outcomes for individuals and ultimately increases the funding burden for all;*
- *A requirement of any funding must be that the advocacy group is independent and not subject to influence by other organisations. Specific consideration should be given to Primary Health Networks, locality based advocacy services and special needs areas such as advocacy services servicing culturally and linguistically diverse communities;*
- *The State government should investigate its powers and/or authority under its public health mandate to legislate that all residential aged care facilities that fall within Queensland borders must have a RN on site 24 hours per day, 7 days a week as minimum. The QNMU notes by way of example, the object of the Public Health Act 2005 (Qld) is ‘to protect and promote the health of the Queensland public’.*²⁶⁷

4.3.4.6 Better cooperation with the Australian Government

The SVHA also acknowledged that aged care services are predominantly funded by the Australian Government, and therefore stated that both levels of government need to work together to:

*ensure the necessary funding and frameworks are in place, and administrative burden and roadblocks removed, so that individuals making the transition are well supported, and service providers are afforded an opportunity to deliver quality and person-centred care.*²⁶⁸

SVHA recommended the two levels of government work together in a complementary manner to coordinate planning and investment in Queensland’s aged care sector, but also suggested the Queensland Government lead the development of a comprehensive ‘master plan’ for aged care and end of life care in the state, in partnership with the Federal Government, local community organisations, and service providers to:

²⁶⁶ Submission 1294, p 2.

²⁶⁷ Submission 1213, p 23.

²⁶⁸ Submission 1280, pp 12-13.

- *identify, plan for, and position complementary services where the need will be in the future*
- *pilot new models of care and services, informed by community input and need*
- *improve coordination of care between primary health, hospitals and aged care providers*
- *afford aged care providers with an opportunity to upgrade their facilities, workforce, and service models to better meet the needs and expectations of residents*
- *attract, train and retain an effective aged care workforce, including building provision into the system to up skill existing health professionals in hospitals and GPs*
- *plan for the better use of technology among individuals to help address geographical distance, and at times, the lack of available location-based age and personal care workforce.*²⁶⁹

LASA suggested that the delivery of aged care services can be improved via a multi-pronged approach, which includes outreach services from the tertiary sector to support the delivery of health care in residential aged care to prevent admissions of residents to hospitals.²⁷⁰

Committee comment

Funding for aged care

The Australian Government's funding model for aged care services does not meet the costs of providing this care. This limits the quality of care that providers can provide. As a consequence of this funding shortfall, an estimated 43 per cent of aged care providers are currently operating at a loss. The lack of funding for aged care is also starving vital pilot projects within the aged care industry which are vitally important for achieving better standards of care and driving efficiency improvements.

In addition to current funding issues in aged care, it is not clear how the projected increase in demand for aged care services will be met in future. The aged care funding model clearly requires a radical rethink.

Interface between the aged care system and public health systems

The interface between aged care provided by the Australian Government and the primary and acute health care systems provided by state and territory governments is a critically important one for people receiving aged care. The complexities of both systems, combined with the separation of funding responsibilities, impact on the care given and imposes additional costs for care recipients and government.

Initiatives already implemented by the Queensland Government to improve this critical interface show promise. They include the deployment of nurse navigators in aged care and the Residential Aged Care Facility Acute Care Support Services which enables acute care to be delivered in residential aged care settings.

A number of further e-health initiatives are also improving patient outcomes including: the Integrated Electronic Medical Record (ieMR) project; and the Viewer, which provides health service and care providers with improved to a wide range of patient information.

Interface between hospitals and residential aged care facilities

The quality and dignity of care for the elderly is constantly being compromised by poor relationships between hospitals and aged care facilities.

Some movement of the elderly between aged care facilities and hospitals may be linked to their shared funding responsibilities between the Australian and state/territory governments which provide

²⁶⁹ Submission 1280, p 10.

²⁷⁰ Submission 1283, p 5.

incentives to 'game' patient care so it is funded by someone else. Given the projected increases in aged care, it is imperative that these issues are resolved.

Access to general practitioners, specialists and allied health professionals

Older people in aged care, particularly those living in residential aged care facilities, should not lose their access to medical and allied health care when they move to a residential aged care facility, but they often do. This in spite of their elevated need for care. Areas where access to services is particularly poor include dental care, mobile x-ray, mental health support, hospital outreach for complex care and after-hours palliative care. This needs to change.

At least some of the blame for these difficulties must rest with the remuneration arrangements under the Medicare Benefits Scheme. These arrangements act as a disincentive for general practitioners to visit patients at residential care facilities. This is because the payment provided under the Medicare Benefits Scheme does not reflect their cost to provide that care.

The Australian Government should review the payment amounts provided under Medicare Benefits Scheme item numbers for care for older people in residential facilities and in the community, and ensure they provide reasonable compensation for doctors, and ensure that the items are also available to a wide range of allied health services that are providing care of aged care recipients. The committee has also proposed some lifting of restrictions on prescribing be considered so nursing staff at residential care facilities can prescribe some medications and order tests for residents.

Better funding and incentives are required for the delivery of allied health services in residential aged care facilities - particularly physiotherapists.

Recommendation 1 Trial of nurse practitioners

The committee recommends that the Australian Government allocate funding through the Primary Health Networks in Queensland to trial the use of nurse practitioners in residential aged care facilities. The trial could include expanding their scope of practice to prescribe certain medications and order certain pathology testing for residents in consultation with general practitioners.

Recommendation 2 Consistency of access to health services while in residential aged care

The committee recommends that the Australian Government in consultation with individual providers ensure that residents in residential aged care facilities enjoy the same level of access to health service providers as other elderly in their local community living outside of those facilities.

Recommendation 3 Review of item numbers for visits by general practitioners to residential care

The committee recommends that the Australian Government review the schedule of item numbers that general practitioners, specialists and other allied health professionals can access to claim the costs of care they provide for patients, and their travel to and from residential aged care facilities or patients' homes and the formula used for calculating payment amounts. In reviewing the formula, the government should ensure the formula provides reasonable compensation for doctors and other health professionals for their time whilst removing incentives for practitioners to bulk visit facilities.

Committee comment

Opportunities for the Queensland Government to take a lead role to improve age care

Stakeholders supported initiatives implemented by Queensland Health and hospital and health services to improve the interface between aged care and the public health and hospital system.

The two programs implemented by the Queensland Government showing promise for improving the standard of aged care being provided are the Comprehensive Aged Residents Emergency and Partners in Assessment Care and Treatment (CARE-PACT) model of care and the nurse navigator model of care.

Recommendation 4 Care for frail elderly residents in aged care facilities

The committee recommends that Queensland Health examine opportunities to expand programs such as the Comprehensive Aged Residents Emergency and Partners in Assessment Care and Treatment program that focus on streamlining the care pathway for the frail elderly residents of aged care facilities.

Recommendation 5 Utilisation of nurse navigators in aged care to improve access to primary care

The committee recommends that the Queensland Government explore opportunities to better utilise nurse navigators in aged care to improve access to primary care for older people and supplement the care provided by general practitioners.

Committee comment**Better communications and access to patient records**

A number of stakeholders commented on the absence of good communications between hospitals and ambulance service workers, residential aged care facilities and general practitioners and how this disrupts the continuity of care for elderly patients. These problems appear to be particularly significant for residential aged care facility residents as they enter or exit hospitals and during their discharge from hospitals. There are clearly opportunities where the sharing of patient/resident information between residential aged care facilities, general practitioners, hospitals and ambulance service staff could lead to worthwhile benefits in terms of patient care and efficiency gains for all parties involved. There is also scope to make better use of modern communication technologies to ensure prescription information and other patient information is provided to clinical care staff at residential aged care facilities, and that these records are shared efficiently and reliably with patients' general practitioners.

Given Queensland's expertise in integrated electronic medical record systems and providing electronic access to patient records using The Viewer, this is an aspect of aged care where Queensland could make significant inroads.

Recommendation 6 Sharing of electronic patient/resident records

The committee recommends that the Queensland Government, through Queensland Health, explore the feasibility of improving access to The Viewer to enhance the sharing of electronic patient/resident records between residential aged care facilities, hospitals, ambulance service staff, general practitioners and other health service providers to improve the continuity of care for residents/patients.

5 Accessing aged care services

5.1 My Aged Care

5.1.1 Background to My Aged Care

In 2011, the Productivity Commission highlighted difficulties faced by users navigating the highly complex aged care system.²⁷¹ The commission's report subsequently proposed that a gateway agency be established to provide information, assessment of needs and entitlement to care and support services, care coordination and carer referral services, to be delivered via a regional network.²⁷²

The My Aged Care website and contact centre were established in 2013 as the entry point to the Australian Government-subsidised aged care system. The My Aged Care contact centre was initially an information-only service for people to learn about aged care processes and services over the phone.²⁷³

My Aged Care was subsequently expanded from 1 July 2015 to become the gateway through which older people access government-funded aged care services. The changes included:

- a central client record
- extending the role of the contact centre, from information provision to also include
 - registration and screening of consumers
 - referring eligible consumers for a face-to-face assessment by either the Regional Assessment Service or an ACAT
 - assisting consumers to find available and appropriate government-funded aged care services, where required
- the Regional Assessment Services, whose main function is to conduct face-to-face assessments for those who seek entry level support at home, provided under the CHSP
- match and refer capability—an electronic system to support assessors to identify and assist in matching eligible consumers to service providers in their local area
- web-based My Aged Care portals for clients, assessors, service providers and the contact centre
- the ability for service providers to self-manage information about the services they deliver.²⁷⁴

The Tune Review in 2017 identified numerous issues with the My Aged Care gateway, and recommended that the Australian Government:

- improve the functionality and performance of the My Aged Care ICT platform with particular emphasis on improving information-sharing between My Aged Care and other government agency and provider ICT systems
- introduce aged care system navigator and outreach services to assist consumers who have difficulty engaging through the existing channels, such as those with complex needs and those with limited access to technology, to effectively engage with My Aged Care

²⁷¹ Productivity Commission, *Caring for Older Australians*, Report No. 53, 2011, Vol 1, p XXIX, <https://www.pc.gov.au/inquiries/completed/aged-care/report>.

²⁷² Productivity Commission, *Caring for Older Australians*, Report No. 53, 2011, Vol 1, p LXXXV, <https://www.pc.gov.au/inquiries/completed/aged-care/report>.

²⁷³ David Tune AO PSM, *Legislated Review of Aged Care 2017*, p 124, <https://www.health.gov.au/sites/default/files/legislated-review-of-aged-care-2017-report.pdf>.

²⁷⁴ David Tune AO PSM, *Legislated Review of Aged Care 2017*, pp 124-125, <https://www.health.gov.au/sites/default/files/legislated-review-of-aged-care-2017-report.pdf>.

- invest in regular advertising and awareness activities for My Aged Care, to explain the process for accessing government-funded aged care services, due to low levels of community awareness about aged care and of My Aged Care, and
- continue to improve the My Aged Care website for consumers and providers by making the design and layout easier to use and providing information in more accessible, plain-English formats.²⁷⁵

An improved My Aged Care website was launched on 24 June 2019. According to the Department of Health:

*The new website is much easier to navigate, better supporting older Australians, their families and carers to find information and search for aged care providers. The new website was developed based on feedback from a wide range of users and stakeholders. It also provides improved information about services, and greater transparency in relation to pricing.*²⁷⁶

The Australian Government has advised it will introduce a face to face service to assist and guide older Australians and their families with navigating the aged care system, including outreach services to help older Australians make informed choices about their aged care needs. Four programs will be trialled:

- 30 aged care information hubs to provide locally targeted information and build people's capacity to engage with the aged care system
- 20 community hubs where members support each other in navigating aged care and healthy ageing
- six full-time specialists placed in consumer-focused organisations to offer one-on-one support for vulnerable people, and
- six full-time aged care Financial Information Support Officers (FISOs) in the Department of Human Services – to complement the existing generalist FISO service – to give additional support to people with the complex financial decisions they need to make when entering aged care.²⁷⁷

According to the Department of Health, these measures will focus on helping people who face barriers to accessing aged care and are vulnerable,²⁷⁸ and will help people to:

- understand what aged care services are available to meet their needs
- connect with My Aged Care, and
- choose and access aged care services.

In other work, COTA Australia have partnered with 30 other organisations to pilot and evaluate 62 different navigator activities across the country and will report back to the Department of Health on

²⁷⁵ David Tune AO PSM, *Legislated Review of Aged Care 2017*, p 15, <https://www.health.gov.au/sites/default/files/legislated-review-of-aged-care-2017-report.pdf>.

²⁷⁶ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 18, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

²⁷⁷ Australian Government, Department of Health, Aged Care System Navigator Measure, <https://www.health.gov.au/initiatives-and-programs/aged-care-system-navigator-measure>; Leading Age Services Australia, LASA Federal Budget 2018-19 Analysis For Lasas Members, 11 May 2018, <https://lasa.asn.au/wp-content/uploads/2018/05/18-05-11-2018-19-FINAL-BUDGET-ANALYSIS-FOR-MEMBERS.pdf>.

²⁷⁸ Australian Government, Department of Health, Aged Care System Navigator Measure, <https://www.health.gov.au/initiatives-and-programs/aged-care-system-navigator-measure>.

the most effective ways to share information with vulnerable older people. The Aged Care Navigator pilot is funded until June 30, 2020.²⁷⁹

5.1.2 Operation of My Aged Care

The My Aged Care contact centre operates nationally from 8am–8pm on weekdays, and 10am–2pm on Saturdays. A separate helpline is available for My Aged Care assessors and service providers.²⁸⁰

According to the website, My Aged Care currently provides:

- information about aged care to consumers, family members and carers
- information for service providers
- online service finders that provide information about aged care service providers and assessors, and
- online fee estimators for pricing on home care packages and residential care.²⁸¹

My Aged Care also provides an entry point to the aged care system through access for consumers to compliance information about providers and assessment and referral systems.²⁸²

In 2018–19, the My Aged Care contact centre answered 1,471,748 calls and the website had a total of 3,678,272 visits.²⁸³

5.2 Assessment for aged care services

When consumers contact My Aged Care looking for aged care support, they are registered and undergo a screening conversation where they may be referred for either a home support assessment by a Regional Assessment Service (RAS), a comprehensive assessment by an ACAT under the Aged Care Assessment Program or, where appropriate, a referral to health or other support services.²⁸⁴ For the Multi-Purposes Services Program and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program, assessment is based on clinical need and is undertaken by a health professional.²⁸⁵

5.2.1 Regional Assessment Services

RAS provide assessments and approval for people seeking basic support at home under the CHSP to assist with maintaining greater independence and wellbeing.²⁸⁶ This program targets frail senior Australians aged 65 years or older (or 50 years or older for Aboriginal and Torres Strait Islander people), however may also include prematurely aged people 50 years or older (or 45 years or older for

²⁷⁹ COTA Australia, Aged Care Navigators, <https://www.cota.org.au/information/aged-care-navigators/>.

²⁸⁰ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 18, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

²⁸¹ <https://www.myagedcare.gov.au/>.

²⁸² Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 16, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

²⁸³ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 18, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

²⁸⁴ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 9.

²⁸⁵ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 10.

²⁸⁶ Queensland Health, correspondence dated 23 January 2019, p 7; Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 9.

Aboriginal and Torres Strait Islander people) who are on a low income and who are homeless or at risk of homelessness.²⁸⁷

Following an assessment, a person may be:

- referred for CHSP services
- recommended to receive linking support or reablement services
- referred for a comprehensive assessment
- provided with information.²⁸⁸

The RAS are independent, non-government or private assessment organisations engaged by the Australian Government through contractual arrangements.²⁸⁹ The RAS program is not linked to the Aged Care Act.²⁹⁰ In 2018–19, the Australian Government allocated funding of approximately \$114.8 million for 17 RAS providers to deliver assessment services in all states and territories. RAS providers completed 264,377 assessments in 2018–19.²⁹¹

5.2.2 Aged Care Assessment Program

The Aged Care Assessment Program (ACAP) is a cooperative working arrangement between the Australian and state and territory governments to operate ACATs across Australia. The core objective of the ACAP is to comprehensively assess the care needs of frail older people and to assist them to gain access to the most appropriate types of care, including approval for Australian Government subsidised care services.²⁹² This program targets people with more complex needs requiring access to higher intensity care.²⁹³

The Australian Government enters into contractual arrangements with state and territory health departments for the provision of ACAT services. ACAT team members are delegates of the Secretary of the Department of Health for the purposes of determining care recipient eligibility under the Aged Care Act.²⁹⁴ Approximately \$128 million was allocated for ACAT purposes in 2018–19.²⁹⁵

²⁸⁷ Australian Department of Health, *Streamlined consumer assessment for aged care discussion paper*, 2018, p 4, https://consultations.health.gov.au/in-home-aged-care-division/streamlined-consumer-assessments-for-aged-care-ser/supporting_documents/Discussion%20Paper%20%20Streamlined%20Consumer%20Assessment%20for%20Aged%20Care.pdf.

²⁸⁸ Australian Department of Health, *Streamlined consumer assessment for aged care discussion paper*, 2018, pp 5, <https://consultations.health.gov.au/in-home-aged-care-division/streamlined-consumer-assessments-for-aged-care-ser/>.

²⁸⁹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 9.

²⁹⁰ Australian Department of Health, *Streamlined consumer assessment for aged care discussion paper*, 2018, p 4, <https://consultations.health.gov.au/in-home-aged-care-division/streamlined-consumer-assessments-for-aged-care-ser/>.

²⁹¹ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 20, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

²⁹² Queensland Health, correspondence dated 23 January 2019, p 6.

²⁹³ Australian Department of Health, *Streamlined consumer assessment for aged care discussion paper*, 2018, p 4, <https://consultations.health.gov.au/in-home-aged-care-division/streamlined-consumer-assessments-for-aged-care-ser/>.

²⁹⁴ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 10.

²⁹⁵ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 20, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

The ACATs utilise My Aged Care to assess the care needs of senior Australians and make referrals to services or to provider waitlists.²⁹⁶ ACATs are multi-disciplinary teams who conduct face-to-face assessments with clients to determine their eligibility for residential aged care, residential respite care, home care, short-term restorative care and transition care to best meet their needs.²⁹⁷ They assess the care needs of a consumer taking into account their physical, medical, psychological, cultural, social and restorative care needs. ACATs can also refer people to other programs and services that do not require approval under the Aged Care Act, such as CHSP services.²⁹⁸

During the assessment, the assessor and client work together to establish a support plan that reflects the client's strengths and abilities, areas of difficulty and the support that will best meet their needs and goals. This will include the consideration of formal and informal services as well as reablement pathways. A support plan review occurs when a client's care needs or circumstances has changed.²⁹⁹

5.2.2.1 *Provision of ACAT services in Queensland*

Queensland Health is the approved provider of the ACATs in Queensland and currently operates 14 ACATs.³⁰⁰

Under the *Aged Care Assessment Program Agreement 2018-20*, Queensland Health provides quarterly performance reports to the Commonwealth to demonstrate its achievement of agreed key performance indicators and performance expectations. Key performance Indicators measure timeliness of assessment throughout the Aged Care Assessment pathway.³⁰¹

According to Queensland Health, Queensland routinely meets most key performance Indicators as defined in the agreement with the Commonwealth, ‘demonstrating timely assessment of clients in the hospital and community’.³⁰²

However, in terms of the timeliness of assessments, Queensland Health advised the committee:

As a result of the volume of people waiting on the national queue for home care packages, coupled with their care needs not being met in a timely manner due to their lack of appropriate package, the volume of Support Plan Reviews continues to increase. The increase in Support Plan Reviews results in further pressures on Aged Care Assessment Teams.

*The volume of referrals is also steadily increasing. The increase in referrals is a result of increasing community awareness of Commonwealth supports and the proportion of eligible clients increasing in line with the growing population of Queensland residents over 65 years.*³⁰³

5.2.3 Changes to the assessment process

The Tune Review reported stakeholder concern about the complexity and duplication within the screening pathway and about the timeliness, quality and consistency of the assessment process under My Aged Care. The Tune Review recommended a more rigorous and integrated assessment model, including that the Australian Government:

²⁹⁶ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 20, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

²⁹⁷ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 9; Queensland Health, correspondence dated 23 January 2019, p 6.

²⁹⁸ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 9.

²⁹⁹ Queensland Health, correspondence dated 28 October 2019, attachment, p 1.

³⁰⁰ Queensland Health, correspondence dated 28 October 2019, attachment, pp 1-2.

³⁰¹ Queensland Health, correspondence dated 28 October 2019, attachment, p 2.

³⁰² Queensland Health, correspondence dated 28 October 2019, attachment, p 2.

³⁰³ Queensland Health, correspondence dated 28 October 2019, attachment, p 3.

- trial a simplified My Aged Care assessment process for consumers seeking a short-term single, simple service
- integrate the RAS and ACAT assessment workforces, and
- following the review of the aged care funding instrument, integrate residential aged care funding assessment with the combined RAS and ACAT functions, independent of aged care providers.³⁰⁴

In the 2018–19 Budget, the Australian Government announced that it will design and implement a new framework to streamline consumer assessments for all aged care services to address the issue of duplication and inefficiency within the current assessment process.³⁰⁵ Under the new arrangements, a single national assessment workforce and a network of assessment organisations will assess eligibility for access to all government-funded aged care services, replacing the RAS and ACAT workforces.³⁰⁶

The new arrangements are planned to start in April 2021, with the current assessment services provided by the RASs and ACATs to continue until then.³⁰⁷

5.3 Issues with access and navigating the aged care system

A common theme heard throughout the inquiry was the difficulties older people still face navigating the aged care system via My Aged Care and the potential for people to miss out on services due to these difficulties, despite improvements to the system. The committee also heard that the information provided is not always accurate or up-to-date, and that more information, which is easier to access, is needed to assist older people navigate their options.

The Royal Commission heard similarly evidence of difficulties faced by people navigating the aged care system. The Royal Commission’s interim report noted:

*A number of people will seek out aged care services either independently or at the urging of family, friends, doctors and hospitals. Unfortunately, it is at this point, when the aged care system should be welcoming and easy to navigate, that the first problems emerge.*³⁰⁸

...

Navigating aged care requires an older person and their carer to make difficult emotional, financial, health and housing-related decisions, often under stress and time pressures, and with

³⁰⁴ Australian Government, Department of Health, Streamlined Consumer Assessment for Aged Care, <https://consultations.health.gov.au/in-home-aged-care-division/streamlined-consumer-assessments-for-aged-care-ser/>; David Tune AO PSM, *Legislated Review of Aged Care 2017*, p 68, <https://www.health.gov.au/sites/default/files/legislated-review-of-aged-care-2017-report.pdf>.

³⁰⁵ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 21; <https://consultations.health.gov.au/in-home-aged-care-division/streamlined-consumer-assessments-for-aged-care-ser/>.

³⁰⁶ Australian Government, Department of Health, New Aged Care Assessment Arrangements, https://www.health.gov.au/health-topics/aged-care/aged-care-reforms-and-reviews/new-aged-care-assessment-arrangements?utm_source=health.gov.au&utm_medium=redirect&utm_campaign=digital_transformation&utm_content=programs/streamlined-consumer-assessment-for-aged-care.

³⁰⁷ Australian Government, Department of Health, New Aged Care Assessment Arrangements, https://www.health.gov.au/health-topics/aged-care/aged-care-reforms-and-reviews/new-aged-care-assessment-arrangements?utm_source=health.gov.au&utm_medium=redirect&utm_campaign=digital_transformation&utm_content=programs/streamlined-consumer-assessment-for-aged-care.

³⁰⁸ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 2, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

*limited prior exposure to the system. It is obvious to us that there should be more services made available to people to navigate aged care. Having a single front door to the aged care system is a positive change, but help to find that door and then navigate the labyrinth beyond is required. People need integrated, face-to-face support and linking services, with local knowledge, to help them access the right service.*³⁰⁹

The Royal Commission reported the following main barriers people face when trying to access aged care services:

- *the difficulty in finding useful information about what options are available where they live*
- *the difficulty in working out how to coordinate services which may be delivered by different providers*
- *the time-consuming, repetitive efforts that have to be made in order to access a home-based service or transition into residential care.*³¹⁰

5.3.1 My Aged Care

The committee heard from numerous submitters and witnesses about the difficulties experienced by those navigating the aged care system via My Aged Care in order to access services.³¹¹ Older people's abilities to use the system and its capacity to meet the needs of older people was raised as an issue, particularly in relation to computer literacy, English literacy levels and those with special needs.

For example, PCQ submitted:

*Accessing aged care services is a complex, multi-step process which requires good English language skills, high levels of literacy and patience to navigate. The My Aged Care website is not user friendly and contact with the call centre can leave consumers frustrated.*³¹²

The COTA Queensland submission noted that in a survey they undertook of older people in 2018, some questioned whether call-centre staff are trained to work with older people who have hearing problems or other health issues that make talking on the phone difficult.³¹³

LASA raised issues with the mode of delivery of My Aged Care, submitting:

*While MAC [My Aged Care] is slowly improving as a portal for aged care consumers, implementation (along with the underlying complexity of aged care system's structure, programs, rules, etc.) has caused significant confusion for aged care consumers and their families and referrers. There are limitations with the mode of delivery (web-based portal and telephone help line) and there have been implementation issues within these modes.*³¹⁴

CentaCareCQ also referred to the difficulties older people may face if they aren't internet savvy:

People seeking aged care services (potential clients) are still struggling to use My Aged Care – while there have been some improvements since it was first introduced, it's still confusing and frustrating for people, particularly those who are not regular users of online services. The

³⁰⁹ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 144, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

³¹⁰ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 137, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

³¹¹ See, for example, submissions E1693, 1235, 1288, 1297, 1301, 1304, 1891.

³¹² Submission 1891, p 43.

³¹³ Submission 1304, p 18.

³¹⁴ Submission 1283, attachment, p 7.

*webinar for providers has helped, but as it's aimed at providers, that doesn't help people seeking services.*³¹⁵

Brisbane South PHN also referred to the difficulties faced by older people without family advocates or who are experiencing or are at risk of homelessness.³¹⁶

COTA Queensland also advised that some of their survey participants commented that My Aged Care is useful for providing general information, but not for seeking answers to specific questions.³¹⁷

Concerns were raised that older people may be missing out on services because of the difficulties they face accessing and navigating My Aged Care. For example, Queensland PHNs submitted:

*My Aged Care is not meeting the needs of older people and for those who are using it, the satisfaction rates (while within standards of call centres) are lower than communities expect. Many frail aged people who are living at home report they are not phoning MAC for assessment to the home care services due to cognitive challenges, hearing or dexterity issues and are 'giving up', therefore falling between the cracks and not accessing ANY in home support services.*³¹⁸

ADA Australia advised that many potential aged care consumers are missing out on opportunities to access home care because they have not read or understood the complex information provided to them by My Aged Care with regards to the access processes and associated deadlines.³¹⁹

Submitters working in health care advised that even health care professionals struggled with the My Aged Care system. For example, the Member for Greenslopes, Mr Joe Kelly MP, stated that in his experience volunteering as a registered nurse in a local health social enterprise, he found the system 'difficult to navigate, disjointed, time consuming and ultimately not centred on solving problems for the patient'.³²⁰

Queensland PHNs similarly submitted that 'Even those with good health literacy, and those who work in the sector still struggle when seeking care for themselves or their families'.³²¹

Queensland PHNs referred in particular to the experience of hospital staff using My Aged Care, stating:

*Private and public hospitals struggle to navigate My Aged Care for safe discharge of their patients back home. The proliferation of system navigators (such as those in aged care, mental health and disability services) is reflective of the complexity of the system and the difficulty that patients and their carers have in understanding and accessing different parts of the system. Simplifying and integrating the different system components should be a reform goal.*³²²

Stakeholders also questioned the reliability of information on the My Aged Care website. For example, CentaCareCQ submitted:

An issue that comes up for us fairly regularly is that the information on the portal about what services are available in a particular area is not accurate. As an example, people call us because they see our advertisement, for yard maintenance. The myagedcare service finder has listed a variety of providers that are situated outside the local area. When clients contact these providers they are told they do not have capacity or they do not deliver in the area. Clients are telling us that they don't trust what's on the portal and just call us directly. We end up doing the work of

³¹⁵ Submission 1297, p 1.

³¹⁶ Submission 1212, p 1.

³¹⁷ Submission 1304, p 18.

³¹⁸ Submission 1301, p 2.

³¹⁹ Submission 1243, p 3.

³²⁰ Submission 1235, p 2.

³²¹ Submission 1301, p 2.

³²² Submission 1301, p 4.

*linking them into appropriate services (ours or other service providers, depending on where they are and what they need). This is work we are not funded to do.*³²³

In COTA Queensland's survey some participants stated that My Aged Care lacks detail and also questioned its reliability, particularly where it relates to service providers.³²⁴

The complexity of navigating My Aged Care and the need to engage a broker or navigator was also raised by submitters. COTA Queensland explained to the committee:

In recent years there has been an emerging industry of user-pays aged care brokers who offer to handle all the paperwork and locate a service provider to meet an individual's needs.

*Both the Aged Care Navigator Trials and the emergence of aged care brokers are evidence of the complexity of Australia's aged care system. A person-centred system should not require a navigator to help consumers ensure the system can meet their needs. While COTA Queensland supports the Australian Government's decision to trial system navigators and anticipates the navigators will fill a great community need, we call for ongoing efforts to simplify the system and improve its consumer focus.*³²⁵

Likewise, Dr David MacFarlane submitted:

*Entry into and selection of care facilities is a complex and poorly defined process, eventually requiring engagement of a broker. The remuneration of the broker was unclear. The whole process is ill defined and not streamlined.*³²⁶

Ms Lenore Keough commented on the need for more support when older people are exercising their choice of provider. Ms Keough informed the committee of her experience:

*Finally, while the ACAT assessor who is handling my mother's case has been extremely kind and helpful and has made many aspects of the situation much easier, the overall process of going through the system of applying, being assessed, and then being responsible for sourcing services from suppliers is absolutely bamboozling to my mother, and I daresay to many if not most elderly people trying to navigate it. It all sounds very fine that the end user is being given choice and control - but what they need more of is support and assistance and advice to go along with their ability to choose. It's currently just extremely difficult, confusing and stressful.*³²⁷

COTA Queensland advised that in their survey of older Queenslanders, participants were asked to comment on the availability of reliable information regarding aged care services. Several participants commented that they have little idea about what services are available and what services are likely to be most suitable for them. Similarly, COTA Queensland referred to a report by the ACFA which noted that some consumer groups are not aware of My Aged Care. In particular, people from Aboriginal and Torres Strait Islander communities and culturally diverse communities may not know about the system and may need support to navigate the system.³²⁸

Stakeholders also called for more information to be given to older people to assist with their decision making on aged care services and providers. COTA Queensland stated that more information and increased transparency for consumers is required, while Ms Noelene Frances Kidd addressed why more information should be given to older people:

³²³ Submission 1297, p 2.

³²⁴ Submission 1304, p 18.

³²⁵ Submission 1304, p 18.

³²⁶ Submission E1634.

³²⁷ Submission E1741.

³²⁸ Submission 1304, p 19.

*Aged in hospital are sometimes faced with the problem that they are too ill or incapacitated to return home and are told that they must go into an institution for residential care. Many are unwilling, but some realise that it is their only future course. They or their relatives, frequently don't have the ability to assess the various facilities which may be available although they may have a list provided to them and may make some cursory visits. They need more information about the residential homes and financial structures in order to assist them in making a decision.*³²⁹

Ms Lynette McClearie observed that information and access to aged care services can be difficult for many older people, and suggested that the solution is to create an '...overseeing and coordinating role of an Aged Care Advocate'. She submitted that:

Advocates could be trained at a Certificate 4 level to link clients, carers and their families with providers of the full range of services needed by the aged.

- *They could be drawn from several pools such as the underemployed, retrenched mature workers and parents wishing to work school hours.*
- *They could assist with technology.*
- *Through weekly brief checks by phone or online, they would assist with access to and updates of services.*
- *Advocates would ideally continue to assist clients and their families to the end of life. They may elect to include training in Palliative services.*³³⁰

Brisbane South PHN commented on the aged care service navigation trials currently underway, submitting:

*The federal government recently established an eighteen month trial of different models of aged care service navigation support across Australia (Brisbane South PHN is a consortium member of the successful COTA tender) to inform the most effective and efficient approach for implementation from July 2020. Hopefully the trials will also shed light on whether the most vulnerable older people (including those from CALD and Indigenous groups) are accessing assessment and services at a proportionate rate to the broader cohort of older people, which may not be the case currently. Better data is required to be able to monitor this more accurately.*³³¹

The Royal Commission also reported evidence that people found My Aged Care difficult to navigate and utilise, noting:

*... the My Aged Care website falls far short of being able to support choice by providing meaningful information or to connect people with services. There is still very little information available to older people or their families to assist them in making choices between services. The information that is available is not clearly set out.*³³²

On the issue of satisfaction with My Aged Care, the Royal Commission found that the Department of Health's performance indicator in 2017–18 for the My Aged Care website was that at least 65% of people using it found it useful or that it met their needs. While this is not a particularly high target, even that target was not met. According to the Royal Commission's Interim Report, it was estimated

³²⁹ Submission 1304, p 10; submission 2562, p 3.

³³⁰ Submission 2652, p 2.

³³¹ Submission 1212, p 1.

³³² Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 133, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

that in 2017-18 barely half (55%) of surveyed users were happy with the service provided by the My Aged Care website.³³³

5.3.2 Assessment process

A number of issues were raised during the inquiry in relation to the assessment process undertaken as part of the My Aged Care entry procedures, including inconsistency in the assessment process, the wait for assessments and reassessments, issues with the information provided and support for older people once they have had their assessment. These issues are similar to those identified in the Tune Review, which was undertaken in 2017.

The AASW Queensland Branch submitted that its members have observed a lack of consistency in the training, skills and professional backgrounds of people involved in the aged care intake process. They stated:

In the first point of contact, the person seeking assistance is connected to an Intake Officer. Intake officers are not qualified social workers or health practitioners and often have administrative backgrounds. They can lack skills to engage with older people who have complex needs and can have limited understanding of the specific social and health needs of particular client groups. This can lead to older people's presenting issues not being well explored and people feeling confused and overwhelmed by the process. Consequently, they are likely to avoid the system entirely and have their needs go unmet.

Following their contact with the intake officers, in most instances a person is referred to the regional assessors. The assessor roles are also non-practitioner roles, with the required qualification being a Certificate III or IV in a community services-related field. Depending on the individual assessor's experience and skills, there can be similar issues and challenges as those experienced at the intake stage.

*If people require three or more services, they are then referred to an Aged Care Assessment Team (ACAT). This is a third point of contact and is the first time people meet with an appropriately trained practitioner. By this stage, people are telling their story for the third time. Overall, this process often results in under-assessment and the person seeking help being under-served.*³³⁴

CentaCareCQ also referred to inconsistency in the assessment process, stating that clients with similar needs in similar situations were being assessed with very different outcomes.³³⁵

The wait for assessments and re-assessments was also raised as an issue by stakeholders. For example, CentaCareCQ submitted that the review/re-assessment process needs to be improved so that providers can assess, plan and implement the necessary services. They told the committee:

*...often times the funds are there, but there is a bottleneck in the assessment process, so the client and the service provider have to wait for "permission" to meet the client's changed needs.*³³⁶

³³³ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 125, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

³³⁴ Submission 1288, p 5.

³³⁵ Submission 1297, p 7.

³³⁶ Submission 1297, p 7.

For home care service, CentaCareCQ argued for more flexibility to transition between packages, so that when a client's needs change, rather than going back to the RAS for assessment, service providers should be given the option to assess then transition as needed.³³⁷

Cancer Council Qld also referred to the wait times for assessments and re-assessments, specifically commenting on the impacts on older people with cancer:

*Older Queenslanders tell us that wait times for Aged Care Assessment Team (ACAT) assessments in some districts can be over four weeks, sometimes between 8-12 weeks to even be assessed, and wait times to be admitted to a facility can be even longer. Due to these wait times, consumers are left with deciding to go into a home with the first available bed, rather than the home they choose or prefer to live in as there are no available beds. These problems are exacerbated for older Queenslanders with cancer and other life limiting conditions. The effects of treatment and/or the condition itself can mean people need additional supports, yet there can be difficulty accessing timely and appropriate assessments (or re-assessments). We are told that additional supports cannot be assessed pre-emptively, even when the impact on a patient is entirely foreseeable. When an older patient receives treatment, they should be able to vary their support services easily and quickly. Assessors should also understand pain management, access to palliative care consultation services and audits of pain management practices.*³³⁸

The Aurukun Shire Council observed that the current backlog of assessments for home care packages, places aged persons in a state of limbo as to their care needs, and suggested that:

*The resources provided to these Assessment Teams needs to be reviewed so that assessments can be completed in a reasonable time and applicants then placed on the national waitlist for funding allocation. As resident health deteriorates, by the time the package is approved, the level of care needs may well have changed.*³³⁹

Mrs Leonie Synnes, a case manager for home care packaged clients, referred to the difficulties she has experienced in having a client's home care package priority levels reviewed due to significant deterioration, and at times, a terminal diagnosis.³⁴⁰

Submitters also suggested that there are issues with the information provided and support for older people once they have had their assessment. CentaCareCQ told the committee:

There have been instances where people have had an assessor visit them, then they call our service and say "we've had our ACAT, can we get services now" – so they haven't understood what the assessor has done, and aren't clear on what should be happening next.

- *We have received referrals for people for CHSP where the request is for 6 types of service. When our staff talk to the clients and ask if they had thought about a home care package, they've said "what's a home care package" – leaving the impression that the clients either aren't being given the information, or that the assessor hasn't noticed that they didn't understand the information*
- *In other instances, clients who are on CHSP and are re-assessed and eligible for a package, refuse the package because they believe it will leave them out of pocket.*³⁴¹

³³⁷ Submission 1297, p 6.

³³⁸ Submission 1303, attachment, p 2.

³³⁹ Submission 1308, p 2.

³⁴⁰ Submission 212, pp 1-2.

³⁴¹ Submission 1297, p 2.

COTA Queensland also referred to the lack of support once a package is approved, stating that people may find it difficult to locate an appropriate service provider.³⁴²

HammondCare provided an example of its dealings with My Aged Care in relation to accessing services once an assessment had been made:

*One particular case outlines this struggle, whereby an elderly man living at home with dementia was approved for a Level 3/4 Home Care Package (HCP) in 2015. At the time, the individual was accessing services but required a more coordinated approach to fulfil his care needs. Upon commencement of the National Prioritisation Scheme in February 2017, the client failed to enter the queue as his carer had difficulty comprehending the system. HammondCare was first introduced to this particular client when he was admitted to hospital for a dementia related incident. We made multiple phone calls to MAC on his behalf, requesting the client be placed on the queue. The MAC representative eventually identified a 'glitch' in the system that could not be easily rectified, meaning the case had to be escalated to more senior personnel. Three home visits and advocacy phone calls were required before the client was able to be placed on the queue.*³⁴³

Brisbane South PHN submitted that integrated assessments may assist with some of these issues, stating:

*The Federal Government's plans to combine RAS, ACAT and potentially ACFI into a streamlined integrated assessment entity provides an opportunity for the Queensland Department of Health, HHSs, PHNs and potentially other non- government agencies with expertise in assessment to come together to consider new models that would work best in the various Queensland contexts.*³⁴⁴

Committee comment

Australia's aged care system is complex and confusing for many users, and needs to be redesigned and simplified. The My Aged Care website and call centre system remain a source of great frustration.

This is problematic for a key government program that should have been designed to be used by older people who may have cognitive impairment and other disabilities due to the effects of illness, advancing age and frailty.

Consumers of aged care services need access to impartial, detailed information in a form they can readily use that helps them make informed decisions about their care needs. For older people who may be suffering cognitive impairment, hearing loss and or speech difficulties, providing information on a website or via the phone may simply be unsuited to their information needs. As a result, people who are entitled to care may be missing out on services and their quality of life may be compromised. Better, clearer information is required for consumers of aged care services and their support people.

Further frustrations involve the assessment processes undertaken as part of the My Aged Care entry procedures. Issues raised with the committee include inconsistencies in the assessment process, the wait times for assessments and reassessments, issues with the information provided and the need for support for older people once they have had their assessment.

Recommendation 7 Redesign of the My Aged Care website

The committee recommends that the Australian Government redesign the My Aged Care website to make it easier for all to use.

³⁴² Submission 1304, p 15.

³⁴³ Submission 1261, p 4.

³⁴⁴ Submission 1212, pp 5-6.

Recommendation 8 Information on aged care

The committee recommends that the Australian Government provide information on aged care in a form that meets the information needs of all users and is targeted at potential recipients of aged care services and their families, including Aboriginal people, Torres Strait Islander people and people from culturally and linguistically diverse communities.

Recommendation 9 Performance targets for assessments and reassessments

The committee recommends that the Australian Government reassess performance targets for the completion of assessments and reassessments as part of My Aged Care to minimise delays.

6 Home Support and Home Care Programs

The committee heard that older Queenslanders generally wish to stay in their own home for as long as possible.³⁴⁵ For example, Ms Krystal Thompson submitted ‘My own first preference for my own age care (70 this year) is to have my needs met in my own home as long as possible and practical’.³⁴⁶ Similarly, Mr John Redman stated ‘I applaud the efforts being made to increase the availability, and scope, of home care with the aim of enabling more Australians to continue to live at home’.³⁴⁷

The submission from COTA Queensland supported this sentiment with results from their recent consultation with stakeholders, telling the committee:

*The demand for home-based care is growing. Most older people prefer to remain in their own home for as long as possible. Almost 60 per cent of people aged over 70 would rather receive formal care at home than in a residential environment. This desire to remain living in one’s own home, or a home-like environment, dominated the preferences for the 183 people who participated in the recent Kitchen Table Discussions engagement with a diverse group of people across Queensland.*³⁴⁸

In 2018–19, almost 1,000,000 people across Australia received home-based care and support, with 840,984 people receiving home support through the CHSP, and 133,439 people receiving care through a home care package.³⁴⁹

People also accessed care through flexible care programs and other aged care services. Some people received care through more than one program.³⁵⁰

In the 2015–16 Budget, the Government announced its intention to establish a ‘single integrated care at home programme’ merging the CHSP with the Home Care Packages Program from July 2018, following consultation with the aged care sector. The aim was to simplify the aged care system for consumers and reduce ‘red tape’ for providers.³⁵¹ However, the 2019-20 Budget extended funding arrangements for CHSP providers by a further two years. This means that the Home Care Packages Program and CHSP will continue to operate as separate programs until at least mid-2022.³⁵²

6.1 Commonwealth Home Support Programme

6.1.1 Overview

The CHSP provides basic, entry-level home support for older people aged 65 years and older (and Aboriginal and Torres Strait Islander people aged 50 years and over) who need assistance undertaking

³⁴⁵ See, for example, submissions 362, 417, 1989, 2557.

³⁴⁶ Submission 417, p 1.

³⁴⁷ Submission 2557, p 4.

³⁴⁸ Submission 1304, p 15.

³⁴⁹ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 11, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

³⁵⁰ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 15, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

³⁵¹ S Morrison (Minister for Social Services) and M Fifield (Assistant Minister for Social Services), *Supporting greater choice for older Australians*, joint media release, 12 May 2015; <https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id:%22media/pressrel/3828043%22>.

³⁵² Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 7, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

Table 6: CHSP services by sub-programme and service type

Sub-programme				
	Community and home support	Care relationships and carer support	Assistance with care and housing	Service system development
Objective	To provide entry-level support services to assist frail, older Australians to live independently at home and in the community.	To support and maintain care relationships between carers and clients, through providing good quality respite care for frail older Australians so that regular carers can take a break.	To support those who are homeless or at risk of homelessness, to access appropriate and sustainable housing as well as community care and other support services, specifically targeted at avoiding homelessness, or reducing the impact of homelessness.	To support the development of the community aged care service system in a way that meets the aims of the CHSP and broader aged care system.
Service types funded	<ul style="list-style-type: none"> • Meals • Other food services • Transport • Domestic assistance • Personal care • Home maintenance • Home modifications • Social support-individual • Social support-group (formerly centre-based day care) • Nursing • Allied health and therapy services • Goods, equipment and assistive technology • Specialised support services 	<ul style="list-style-type: none"> • Flexible respite: <ul style="list-style-type: none"> ○ In-home day respite ○ In-home overnight respite ○ Community access - individual respite ○ Host family day respite ○ Host family overnight respite ○ Mobile respite ○ Other planned respite • Centre-based respite: <ul style="list-style-type: none"> ○ Centre-based day respite ○ Residential day respite ○ Community access-group respite • Cottage respite (overnight community) 	Assistance with care and housing (a person must be older or prematurely aged, aged 50 years and over (45 years and over for Aboriginal and Torres Strait Islander people) on a low income and be homeless or at risk of homelessness as a result of experiencing housing stress or not having secure accommodation).	Sector support and development activities

Source: Australian Government, Department of Health, 2017–18 Report on the Operation of the Aged Care Act 1997, pp 22–23, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

6.1.2 Expenditure

The CHSP is a grant-funded program. In 2018-19, total Australian Government expenditure for the CHSP was \$2.5 billion. The Australian Government also provided \$127.7 million to My Aged Care, RAS, and other initiatives in support of the CHSP. In total, Australian Government expenditure for the

Program in 2018–19 was \$2.6 billion.³⁶³ The Government regulates the supply of services offered through the CHSP through a capped funding amount that is indexed annually.³⁶⁴ In 2018-19, the Australian Government expenditure for CHSP services in Queensland was \$613.9 million.³⁶⁵

Commonwealth Home Support Programme consumers contributed \$219 million, which represents 9.3 per cent of total expenditure on home support.³⁶⁶

6.2 Issues with the Commonwealth Home Support Programme

Stakeholders raised more issues with the home care packages program than the CHSP. However PCQ raised concerns about the provision of CHSP services alongside palliative care services:

*Whilst the CHSP Manual states that ‘State and Territory governments are responsible for the provision and delivery of palliative care and hospice services as part of state health and community service provision responsibilities’, it says ‘CHSP clients are able to receive palliative care services from their local health system in addition to their home support services’. However, My Aged Care staff undertaking screening, Regional Assessment Service (RAS) and Aged Care Assessment Team (ACAT) assessors often dispute whether a CHSP personal care service should be provided when a specialist palliative care service is involved. Lack of consistency about service provision responsibilities at the State/ Territory and Commonwealth levels lead to lack of clarity about eligibility, all resulting in delayed or limited services being provided to older people with a life limiting illness. Often this results in transfer of the person to a residential facility or hospital against their wishes, when adequate support could and should have been provided in the home, at a lesser cost.*³⁶⁷

Concerns about the impact of using the CHSP to top up the home care packages provided to older people are discussed in section 6.4.2.

6.3 Home Care Packages Program

6.3.1 Overview

The Home Care Packages Program commenced on 1 August 2013, replacing the former home care programs – Community Aged Care Packages (CACPs), Extended Aged Care at Home (EACH) packages and Extended Aged Care at Home Dementia (EACH-D) packages.³⁶⁸

The Australian Government subsidises home care packages that help older people with more complex needs to access a range of clinical care, personal care and support services to assist with day-to-day

³⁶³ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 26, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

³⁶⁴ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 31, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

³⁶⁵ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 26, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

³⁶⁶ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 23, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

³⁶⁷ Submission 1891, p 44.

³⁶⁸ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 62, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

activities while continuing to live at home.³⁶⁹ Packages are delivered on a Consumer Directed Care (CDC) basis with consumers having an individualised budget which allows them to decide what type of care and services they purchase and who delivers the services.³⁷⁰ Home care package recipients are not limited to a basic list of services. Approved providers work with each of their clients to select services that best meet each individual's care needs and goals.³⁷¹

The Home Care Packages Program is a more structured, more comprehensive package of home-based support, provided over four levels:

- level 1 – to support people with basic care needs
- level 2 – to support people with low level care needs
- level 3 – to support people with intermediate care needs
- level 4 – to support people with high care needs.³⁷²

Home care consumers may use their package funds to purchase the following:

- personal services, such as help with showering or bathing, dressing and mobility
- support services, such as help with washing and ironing, house cleaning, gardening, basic home maintenance, home modifications related to care needs, transport to help with shopping, doctor visits or attending social activities
- clinical care, such as nursing and other health support including physiotherapy (exercise, mobility, strength and balance), services of a dietitian (nutrition assessment, food and nutrition advice, dietary changes) and hearing and vision services, and
- care management, which involves coordinating care and services that will help consumers achieve the goals identified in their care plan.³⁷³

Home care packages are delivered by service providers who have been approved under the Aged Care Act. This approval requires providers to comply with quality of care, consumer-rights and accountability conditions.³⁷⁴

If a person has been assessed as eligible for a particular level of home care package, but there are no packages of the required level available, the person can be offered a lower level package as an interim

³⁶⁹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 11.

³⁷⁰ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 62, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

³⁷¹ Australian Government, Department of Health, About the Home Care Packages Program, <https://agedcare.health.gov.au/programs/home-care/about-the-home-care-packages-program>.

³⁷² Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 2, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf; Queensland Health, correspondence dated 28 October 2019, attachment, p 1. The framework to guide ACAT assessments to determine the appropriate package level can be found here <https://www.health.gov.au/sites/default/files/documents/2019/12/acat-guidance-framework-for-home-care-package-level-user-guide.pdf>.

³⁷³ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 63, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

³⁷⁴ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 27, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

measure until a higher level package is available. According to the Department of Health, the goal is to connect people with care as soon as possible, given package availability.³⁷⁵ If a client is willing to receive an interim level package it does not mean they will wait longer to receive a package at their approved level and has no impact on their wait time for their approved level package. An interim level package simply allows the client to access care and services while they remain on the queue for their approved package level. Once a package becomes available at a higher package level, the package will be assigned to the client and accepted automatically. The client's provider will receive a notification in the provider portal advising them of the client's new package level. The client will also receive a letter advising them of the change.³⁷⁶

Since February 2017, home care packages have been assigned directly to individuals rather than allocated to providers. This allows older people to direct their package to the provider of their choice as well as change providers.³⁷⁷

Between 30 June 2018 and 30 June 2019, the number of operational approved providers of home care grew from 873 to 928 representing a 6.3 per cent increase.³⁷⁸

For entry to a home care package, the average age was 80.5 years for men and 81.1 years for women.³⁷⁹

6.3.2 Reforms to home care

The Home Care Packages Program has been the subject of significant reform.³⁸⁰ Since 1 July 2015, all home care packages are required to be delivered on a CDC basis, with the goal of providing greater transparency to consumers about what funding is available under their package and how those funds are spent, through the use of an individualised budget. It also aims to give the individual more choice and flexibility about the types of care and services they access and how the care is delivered to best meet their needs.³⁸¹

Since 27 February 2017, people receiving home care packages have had greater control over their funds with the ability to direct their packages to their provider of choice. These changes were introduced under the *Increasing Choice in Home Care* reforms, which moved from a system of requiring providers to apply for home care places to assigning home care packages directly to individuals.³⁸²

³⁷⁵ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 6, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9318.pdf.

³⁷⁶ Australian Government, Department of Health, National Prioritisation System, https://www.health.gov.au/sites/default/files/documents/2020/01/national-prioritisation-system-for-the-home-care-packages-program_0.pdf.

³⁷⁷ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 37, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

³⁷⁸ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 30, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9318.pdf.

³⁷⁹ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 12, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9318.pdf.

³⁸⁰ Australian Government, Department of Health, Home Care Packages Program Reforms, <https://agedcare.health.gov.au/aged-care-reform/home-care/home-care-packages-reform>.

³⁸¹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 12.

³⁸² Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 12.

Previously, funding for Home Care Packages went straight to the service provider and the individual had to find a service with an available package.³⁸³

This change also brought about the introduction of the National Prioritisation System (NPS) in home care.³⁸⁴ According to the Department of Health, the NPS allows for the fairer allocation of packages to clients, based on their individual needs and circumstances, regardless of where they live, and was necessary to address significant variations in waiting periods across Australia. While the total number of packages will continue to increase each year, overall the number of packages at each level will continue to be capped. The national prioritisation process is made up of the:

- national package queue, which determines the order in which eligible consumers are assigned a home care package, and
- package release process, which determines the number and type of packages that can be assigned to clients on the queue at a point in time.³⁸⁵

Clients who are assessed by an ACAT and approved as eligible for a Home Care Package must be approved for a:

- home Care Package level – either 1, 2, 3, or 4 with the package level indicating the current care needs of the client; and
- home care services priority – either medium or high priority with the priority indicating how quickly the client requires the package. The default priority will be medium priority with only a small percentage of clients who are at immediate risk being approved as high priority.³⁸⁶

Individuals approved for a home care package are placed on the NPS until a package becomes available and is assigned to them. ACFA advises that:

*Consumers are placed on the queue according to the date they were approved for home care, and their priority for home care services, supposedly ensuring a consistent and equitable national approach. They are assigned a package when they are the next eligible consumer on the queue at a particular level and priority.*³⁸⁷

The national package queue takes into account two factors:

- the client's priority for home care services as determined by the ACAT during their comprehensive assessment, and
- the date they were approved for home care at a specific package level.³⁸⁸

³⁸³ Hon. Scott Morrison MP, Minister for Social Services and Hon. Mitch Fifield MP, Assistant Minister for Social Services, 'Supporting Greater Choice for Older Australians', joint media release, 12 May 2015, https://parlinfo.aph.gov.au/parlInfo/download/media/pressrel/3828043/upload_binary/3828043.pdf;fileType=application%2Fpdf#search=%22media/pressrel/3828043%22.

³⁸⁴ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 12.

³⁸⁵ Australian Government, Department of Health, National Prioritisation System, https://www.health.gov.au/sites/default/files/documents/2020/01/national-prioritisation-system-for-the-home-care-packages-program_0.pdf.

³⁸⁶ Australian Government, Department of Health, Guidance on Priority for Home Care Services, p 1, https://agedcare.health.gov.au/sites/default/files/documents/06_2018/guidance_on_priority_for_home_care_services_v1.pdf.

³⁸⁷ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 6, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

³⁸⁸ Australian Government, Department of Health, National Prioritisation System,

Care level and priority for home care service are not necessarily linked – a level 4 client will not always have a ‘high’ priority for home care service – they may need a high level of care, but not be at immediate risk for a range of reasons. The priority for home care service is a Delegate decision, similar to the package level decision, and can be appealed by a client if they disagree with the decision.³⁸⁹

A ‘medium’ priority for home care services should indicate that while a client is in need of a Home Care Package, their need is not as urgent, relative to some other clients. A ‘high’ priority for home care services is defined as: Client is considered at urgent and immediate risk in terms of their personal safety or at immediate risk of entry to residential care. The client may have a carer and the carer arrangements are unsustainable or at crisis point.³⁹⁰

The Department of Health releases home care packages regularly to clients who have reached the top of the national queue. The number of packages released at each level takes into account the number of new packages that are available, as well as the number of packages that other clients have left or not accepted in previous weeks.³⁹¹

Since 1 July 2019, all home care providers have been required to publish their pricing information in a new standardised home care pricing Schedule (the Schedule) on the My Aged Care website. The Schedule provides information on the common services and costs under a home care package, to better support people to understand and compare home care pricing information. Providers must also publish their full price list i.e. all pricing information in the schedule as well as information about all the services and costs the provider offers.³⁹²

The Department of Health has advised that longer term arrangements will be considered in the context of the Royal Commission into Aged Care Quality and Safety.³⁹³

6.3.2.1 *Impact of reforms*

According to the ACFA’s *Seventh report on the Funding and Financing of the Aged Care Industry*, the financial performance of home care providers was impacted through the introduction of packages following consumers rather than being allocated to providers. ACFA stated:

These changes have resulted in a very large increase in the number of approved providers (873 in 2017-18 compared with 496 in 2015-16) and in turn greater competition between providers which has resulted in a decline in profit margins. Expenses per consumer for home care providers

https://www.health.gov.au/sites/default/files/documents/2020/01/national-prioritisation-system-for-the-home-care-packages-program_0.pdf.

³⁸⁹ Australian Government, Department of Health, Guidance on Priority for Home Care Services, p 1, https://agedcare.health.gov.au/sites/default/files/documents/06_2018/guidance_on_priority_for_home_care_services_v1.pdf.

³⁹⁰ Australian Government, Department of Health, Guidance on Priority for Home Care Services, p 1, https://agedcare.health.gov.au/sites/default/files/documents/06_2018/guidance_on_priority_for_home_care_services_v1.pdf.

³⁹¹ Australian Government, Department of Health, National Prioritisation System, https://www.health.gov.au/sites/default/files/documents/2020/01/national-prioritisation-system-for-the-home-care-packages-program_0.pdf. The Department of Health reports quarterly on the operation of the queue. The Home Care Packages Program Data Reports can be accessed on the Australian Institute of Health and Welfare’s GEN Aged Care Data website at: www.gen-agedcaredata.gov.au; Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 12.

³⁹² Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 35, <https://www.gen-agedcaredata.gov.au/www.aihwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf>.

³⁹³ Australian Government, Department of Health, Home Care Packages Program Reforms, <https://agedcare.health.gov.au/reform/future-care-at-home-reform>.

*increased by 7 per cent in 2017-18 while income per consumer decreased by around 1 per cent compared with 2016-17.*³⁹⁴

ACFA advised that this led to a significant deterioration in the financial performance of home care providers in 2017-18, stating:

*After several years of relatively stable returns, earnings before interest, taxes, depreciation and amortization (EBITDA) per consumer for home care providers fell by over 60 per cent in 2017-18. After significantly outperforming not-for-profit and government providers in the previous three years, for-profit providers reported the largest fall in financial performance in 2017-18.*³⁹⁵ *Seventy per cent of home care providers achieved a net profit in 2017-18, down from 75 per cent in 2016-17 and 2015-16. Across the sector, providers achieved an average EBITDA of \$1,217 per consumer, a significant decline from \$2,989 for 2016-17 and \$3,055 in 2015-16.*³⁹⁶

...

*Home care is in a period of transition and many providers appear to be still in the process of adjusting their processes and business models to be more responsive to meeting the needs of consumers. The reforms have increased costs for providers and the increased competition, including price competition, has significantly squeezed margins. It appears that a substantial amount of the competition is in attracting new consumers who have been allocated a package, and only a small proportion of consumers are moving between providers. While additional packages will be released, given the large increase in the number of providers, it is likely that there will be a shake-out and a process of consolidation. The beneficiaries of the reforms to home care are the consumers, although some concerns have been raised that the increase in competition has resulted in some providers not only reducing their prices but also the quality of their services.*³⁹⁷

6.3.3 Payments and subsidies

The Home Care Packages Program provides a subsidy towards the total amount of funds available under a home care package. Each level of home care package provides a different subsidy amount. Supplements are also available to eligible approved providers of home care to meet individual needs.³⁹⁸

The Australian Government pays approved providers an amount of home care subsidy on behalf of each eligible care recipient. The home care subsidy for a day is calculated as follows:

1. the basic subsidy amount

³⁹⁴ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 4, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

³⁹⁵ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 3, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

³⁹⁶ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p ix, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

³⁹⁷ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p X, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

³⁹⁸ Australian Government, Department of Health, About the Home Care Packages Program, https://agedcare.health.gov.au/programs/home-care/about-the-home-care-packages-program_

2. plus any primary supplements (oxygen supplement, enteral feeding supplement, dementia and cognition supplement, veterans' supplement)
3. less any reductions in subsidy
4. plus any other supplement (hardship supplement, viability supplement).

The home care subsidy is generally paid monthly and is calculated by adding the amounts due for each recipient for each day of the month, based on the claim form submitted by the provider.³⁹⁹

The government subsidy amount increases as the level of package rises. The table below shows the home care package annual subsidy for each package level as of 30 June 2019.⁴⁰⁰

Table 7: Home care package annual subsidy, by package level at 30 June 2019

Package level	Aged care services for people with:	Annual subsidy amount (\$) paid by the Australian Government*
1	Basic care needs	8,800
2	Low-level	15,500
3	Intermediate	33,700
4	High-level care needs	51,100

*These figures are rounded.

Source: Australian Government, Department of Health <https://www.myagedcare.gov.au/home-care-package-costs-and-fees>.

The table below shows the home care supplements available in 2018-19.

Table 8: Home care supplements available in 2018–19

Supplement Type	Description
Primary supplements	
Oxygen supplement	A supplement paid on behalf of eligible care recipients to reimburse costs associated with provision of oxygen therapy.
Enteral feeding supplement	A supplement paid on behalf of eligible care recipients to reimburse costs associated with provision of enteral feeding.
Dementia and cognition supplement	A supplement paid on behalf of eligible care recipients assessed as having cognitive impairment due to dementia or other causes.
Veterans' supplement in home care	A supplement paid on behalf of care recipients with a mental health condition related to their service. Eligibility for the supplement is determined by the Department of Veterans' Affairs.
Top-up supplement	A supplement paid on behalf of care recipients formerly in receipt of an Extended Aged Care at Home Dementia (EACHD) package, to ensure no disadvantage in funding as a result of the transition to the Home Care Packages Program.
Other supplements	
Hardship supplement	A supplement paid on behalf of post-1 July 2014 care recipients in financial hardship who are unable to pay their aged care costs.
Viability supplement	A supplement paid on behalf of eligible care recipients living in regional and remote areas to assist with the extra costs of providing services in those areas.

Source: Australian Government, Department of Health, 2018–19 Report on the Operation of the Aged Care Act 1997, pp 32–33.

³⁹⁹ Australian Government, Department of Health, Home Care Packages subsidy, <https://agedcare.health.gov.au/aged-care-funding/home-care-subsidy>.

⁴⁰⁰ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 11.

However, consumers may also be asked to contribute towards the cost of their care if they can afford to do so. Consumers can be asked to pay:

- a basic daily fee – the maximum basic daily fee is 17.5% of the single rate of the basic age pension – and/or
- an income-tested care fee – if they are assessed as having sufficient income to contribute to the cost of their care. The income-tested care fee reduces the amount of the subsidy paid by the Australian Government to the provider.⁴⁰¹

The basic daily fee is indexed on 20 March and 20 September each year, at the same time as changes to the age pension.⁴⁰²

There are annual and lifetime limits to how much a consumer has to pay in income-tested care fees. Once these limits have been reached, the Australian Government will pay the consumer's share of income-tested care fees to the provider. Safeguards are also available through the financial hardship provisions administered by the Department of Human Services.⁴⁰³

In addition, providers may charge consumers a package management fee, which covers regulatory-related costs such as issuing monthly financial statements and managing unspent package funds on behalf of consumers.⁴⁰⁴

6.3.4 Supply and expenditure

6.3.4.1 *Supply*

Over the last decade, entries to home care have increased, rising by 130% between 2008–09 and 2017–18, reflecting the increased number of home care packages available.⁴⁰⁵ In 2017–18 there was a significant increase in the number of home care consumers, up to 116,843 from 97,516 in 2016–17, (a 20 per cent increase).⁴⁰⁶ Interestingly, in 2017–18, Queensland had the highest rate of entry to home care services (16.30 per 1,000 people) in the target population (all people aged 65 and over, and Aboriginal and Torres Strait Islander people aged 50–64).⁴⁰⁷ Nationally, in 2017–18, there were around

⁴⁰¹ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 34, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁴⁰² Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 27, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁴⁰³ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 34, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁴⁰⁴ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 63, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁴⁰⁵ Australian Institute of Health and Welfare, GEN Aged Care Data, Explore admissions into aged care, <https://www.gen-agedcaredata.gov.au/Topics/Admissions-into-aged-care/Explore-admissions-into-aged-care>.

⁴⁰⁶ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 6, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁴⁰⁷ Australian Institute of Health and Welfare, GEN Aged Care Data, Explore admissions into aged care, <https://www.gen-agedcaredata.gov.au/Topics/Admissions-into-aged-care/Explore-admissions-into-aged-care>.

54,000 entries into home care. Approximately 10% were admissions to basic care, around 65% entered for low care, 13% for intermediate and 13% for high care.⁴⁰⁸

At 30 June 2019, there were 106,707 people across Australia who were in a home care package.⁴⁰⁹ This was an increase of 14,860 (or 16.2 per cent) from 30 June 2018.

Since the introduction of the NPS, it has been possible to measure the unmet demand for home care packages. The number of people waiting for a package has been increasing since the NPS was implemented in February 2017.⁴¹⁰

The undersupply of home care packages means that there is a wait for a package, whether that be an interim package or the approved package. Estimated wait times at 30 November 2019, for a person with a medium priority approval joining the system for a package by level are provided in the table below.⁴¹¹

Table 9: Estimated wait time for people entering on 30 November 2019, by package level

Package level	First package assignment	Time to first package	Time to approved package
Level 1	Level 1	3-6 months	3-6 months
Level 2	Level 1	3-6 months	12+ months
Level 3	Level 1	3-6 months	12+ months
Level 4	Level 2	12+ months	12+ months

Source: Australian Government, Department of Health, *Home Care Packages Program: Data Report 1st Quarter 2019-20 1 July – 30 September 2019, December 2019*, p 14.

Data from the Department of Health shows that as at 31 December 2018 there was a total of 127,748 people across Australia waiting for a package. This is an increase of approximately 6,000 in the six months since 30 June 2018.⁴¹² By the end of March 2019, this number had risen to 129,038 people waiting for a home care package or waiting for a package at their assessed package level. However, by June 2019, that number had dropped to 119,524 people waiting for a home care package or waiting for a package at their assessed package level.⁴¹³

⁴⁰⁸ Australian Institute of Health and Welfare, GEN Aged Care Data, Explore admissions into aged care, <https://www.gen-agedcaredata.gov.au/Topics/Admissions-into-aged-care/Explore-admissions-into-aged-care>.

⁴⁰⁹ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 31, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁴¹⁰ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 37, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁴¹¹ Australian Government, Department of Health, *Home Care Packages Program: Data Report 3rd Quarter 2018-19 1 July – 30 September 2019, December 2019*, p 14. https://gen-agedcaredata.gov.au/www_ahwgen/media/Home_care_report/Home-Care-Data-Report-1st-qtr-2019-20.PDF.

⁴¹² Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 37, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁴¹³ Australian Government, Department of Health, *Home Care Packages Program: Data Report 3rd Quarter 2018-19 1 January 2019 – 31 March 2019*, September 2019, p 11, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Home_care_report/HCPP-Data-Report-2018-19-3rd-Quarter-March-2019.pdf; Australian Government, Department of Health, *Home Care Packages Program: Data*

At 30 September 2019, there were 62,942 people waiting on a home care package at their approved level, who had not yet been offered access to a lower level package. Of these people, 96.1 per cent had been provided with an approval to access support through the CHSP.⁴¹⁴ This is slight decrease on the previous quarter. At 30 June 2019, there were 72,062 people waiting on a home care package at their approved level, who had not yet been offered access to a lower level package. Of these people, 95.6 per cent (68,900) had been provided with an approval to access support through the CHSP.⁴¹⁵

There was an increase in the figures on people who had been offered an interim home care package while they waited for a package at their approved level. At 30 September 2019, there were 49,295 who had been offered an interim home care package while waiting for their approved package.⁴¹⁶ At 30 June 2019, there were 47,462 people, who were waiting for a home care package at their approved level, who had already been offered a lower level package.⁴¹⁷

According to ACFA, these results may be due to the 2018-19 Budget, which announced a 're-profiling' of home care packages that saw 14,000 additional higher level packages being released sooner than originally planned. Since this budget announcement there have been two additional changes to future home care package releases aimed at further re-profiling of package releases. In the 2018-19 Mid-Year Economic and Fiscal Outlook (MYEFO) the Australian Government announced an additional 10,000 higher level packages to be funded in 2018-19, followed by a further 10,000 packages (including 4,500 higher level packages) included in the 2019-20 Budget for release in 2018-19 and 2019-20.⁴¹⁸

ACFA notes that while the overall effect of these re-profiling changes is to increase the proportion of higher level packages earlier than originally budgeted for (at significant cost to the Budget) and achieve an approximately 50/50 split of higher and lower level packages by 2021-22, the planned growth in total packages numbers by 2021-22 (to 153,437 packages) is broadly in line with the target set in 2012 when the target provision ratio was set at 45 packages per 1,000 people aged 70 and over.⁴¹⁹

At Royal Commission hearings in Adelaide in February and March 2019, the Commissioners heard that the number of people waiting for their approved home care package sat at over 127,000 people, and while the Government website myagedcare.gov.au lists the expected waiting period as 12-plus months for a level 2, 3 or 4 package, the Royal Commission heard that people are likely to be waiting much

Report 4th Quarter 2018-19 1 April – 30 June 2019, September 2019, p 11, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Home_care_report/HCPP-Data-Report-4th-qtr-2018-19.pdf.

⁴¹⁴ Australian Government, Department of Health, *Home Care Packages Program: Data Report 4th Quarter 2018-19 1 April – 30 June 2019*, September 2019, p 11, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Home_care_report/HCPP-Data-Report-4th-qtr-2018-19.pdf.

⁴¹⁵ Australian Government, Department of Health, *Home Care Packages Program: Data Report 4th Quarter 2018-19 1 April – 30 June 2019*, September 2019, p 11, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/Home_care_report/HCPP-Data-Report-4th-qtr-2018-19.pdf.

⁴¹⁶ Australian Government, Department of Health, *Home Care Packages Program: Data Report 1st Quarter 2019-20, 1 July – 30 September 2019*, December 2019, p 14, https://gen-agedcaredata.gov.au/www_ahwgen/media/Home_care_report/Home-Care-Data-Report-1st-qtr-2019-20.PDF.

⁴¹⁷ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 37, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁴¹⁸ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 38, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>. It is also worth noting that the Australian Government announced an additional 10,000 home care packages in response to the Royal Commission's interim report.

⁴¹⁹ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 38, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

longer. For example, the average waiting time for level 4 care in the 2017/18 financial year was 22 months on average.⁴²⁰

The Royal Commission also heard that during the 12 month period ending 30 June 2018, a total of 212,857 people appeared in the NPS for at least some part of the year. Of these people, more than 16,000 died, waiting for a package that they never received.⁴²¹

Addressing the Royal Commission in March 2019, the first assistant secretary in the Home Aged Care Division of the Department of Health, Ms Fiona Buffinton, estimated that it would cost approximately \$2-2.5 billion to clear the current waiting list for home care packages at the approved level.⁴²²

In terms of providers, the not-for-profit group (comprising religious, charitable and community-based providers) delivered the majority of care, providing assistance to 76.2 per cent of people, while for-profit providers delivered care to 16.9 per cent, and government providers delivered care to 6.9 per cent.⁴²³ Since February 2017 when home care packages began being assigned directly to the consumer, rather than allocated to the provider, the mix of provider ownership has significantly altered, along with a significant increase in the number of providers. The for-profits now represent 35 per cent of the sector, up from 21 per cent in 2016-17 and 13 per cent in 2015-16. In contrast, the proportion represented by not-for-profit providers declined to 53 per cent (65 per cent in 2016-17 and 70 per cent in 2015-16).⁴²⁴

6.3.4.2 *Expenditure*

The Australian Government's expenditure on subsidies and supplements for home care packages increased from \$2 billion in 2017-18 to \$2.5 billion in 2018-19, an increase of 21.5 per cent (and up from \$1.65 billion in 2016-17).⁴²⁵

⁴²⁰ Royal Commission into Aged Care Quality and Safety, public hearing transcript, 12 February 2019, Adelaide, p-167; <https://agedcare.royalcommission.gov.au/hearings/Documents/transcripts-2019/transcript-12-february-2019.pdf>; public hearing transcript, 18 March 2019, Adelaide, p-669, <https://agedcare.royalcommission.gov.au/hearings/Documents/transcripts-2019/transcript-18-march-2019.pdf>.

⁴²¹ Royal Commission into Aged Care Quality and Safety, public hearing transcript, 22 March 2019, Adelaide, p-1098, <https://agedcare.royalcommission.gov.au/hearings/Documents/transcripts-2019/transcript-22-march-2019.pdf>.

⁴²² Royal Commission into Aged Care Quality and Safety, public hearing transcript, 22 March 2019, Adelaide, p-1058, <https://agedcare.royalcommission.gov.au/hearings/Documents/transcripts-2019/transcript-22-march-2019.pdf>.

⁴²³ Australian Government, Department of Health, 2017-18 Report on the Operation of the *Aged Care Act 1997*, p 25, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁴²⁴ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 23, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁴²⁵ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 33, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf; Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 11; Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 71, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

Consumers of home care contributed \$122 million toward the cost of their care through basic daily fees and income tested fees, which represents 5.9 per cent of home care provider's revenue.⁴²⁶

6.4 Issues with the Home Care Packages Program

One of the major issues consistently raised during the inquiry was the wait for home care packages. Stakeholders also raised issues with the administration and delivery of the packages and the adequacy of the packages to meet a person's needs.

6.4.1 Wait for home care packages

Many stakeholders raised the issue of long waiting times for a home care package to become available, particularly at levels 3 and 4, as well as the impact waiting has on older people. They also raised as an issue the inadequacy of supplying older people with a lower level package while waiting for their allocated package.⁴²⁷

For example, the QNMU submitted:

*The waiting times for a community care package can be unacceptably long... the home care packages situation is one where older Queenslanders have to navigate a difficult My Aged Care system, often wait considerable time for assistance due to the queueing approach to package allocation and then often not get the level of care they require...Despite commitments by the Federal Government to increase funding for more home care places the National Prioritisation System essentially creates a queue for places.*⁴²⁸

The QNMU called for a significant review and restructuring of the allocation and delivery of home care packages as a matter of urgency, providing the following analogy:

*These issues are analogous to a patient presenting at a department of emergency medicine and being told that due to a queuing process they cannot be seen for some months, and if their problem is serious, it may take even longer. If this were to happen in the health sector there would be an outcry, yet this situation remains the case in the aged care sector.*⁴²⁹

Stakeholders advised that the long wait can result in an older person's condition deteriorating, and that person subsequently being prematurely and avoidably hospitalised, moved into an RACF, or they may die, before receiving their appropriate package.⁴³⁰

For example, PCQ submitted:

*When an older person is assessed as eligible for a Home Care Package, they often have to wait until a package becomes available. This can take up to two years. The person often deteriorates significantly, requiring a higher level of care, admission to acute care or admission to a residential facility. This situation places an increasing burden on families who are filling the 'care' gap in the meantime.*⁴³¹

⁴²⁶ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 23, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁴²⁷ For example, see submissions 1207, 1212, 1233, 1243, 1259, 1261, 1276, 1280, 1288, 1297, 1540, 1891, 1301, 1309.

⁴²⁸ Submission 1213, p 13.

⁴²⁹ Submission 1213, p 16.

⁴³⁰ See, for example, submissions 414, 1243, 1276, 1281, 1287, 2660.

⁴³¹ Submission 1891, pp 42-43.

For older Australians living with a life limiting illness, particularly when prognosis is difficult or already assessed as short, PCQ told the committee that the wait times to receive a home care packages usually mean that:

- *the person has passed away prior to receiving the care they were assessed as requiring;*
- *periods of hospitalisation are extended due to the lack of support for them to return home;*
- *people move to residential aged care against their and their families wishes, who could otherwise be supported in the community.*⁴³²

National Seniors Australia made a similar claim, stating:

*Consumers are waiting more than 12 months to access Level 2, 3 and 4 packages, with many being forced to enter residential care or worse, dying, while waiting for higher level packages.*⁴³³

Brisbane South PHN referred to the significant wait for home care packages, particularly higher levels of home care packages (levels 3 and 4), and its impact on family as well, submitting:

*People are having to exist with lower level packages (or no formal support) with more support from often stressed family members, requiring more hospitalisations, or prematurely entering residential aged care.*⁴³⁴

In a frank exchange with the committee, Ms Suzanne Greenwood, Chief Executive Officer of Catholic Health Australia told the committee:

... this week, Catholic Health Australia held an aged-care forum in Canberra. We had a number of representatives from the Department of Health speaking. They said that at the moment the waitlist for a person to receive a level 4 package is more than two years after they become qualified and entitled to access it. This is two years for people who have high-level care needs and are waiting to get the care they deserve.

*That is shocking because the life expectancy for many of these individuals needing a level 4 package will be less than two years. What is the reality of that list? Is it six years? Is it 10 years? It is just shocking. Accordingly, Catholic Health Australia recommends that the key focus of this inquiry really should be to explore and recommend options for ensuring aged-care residents have timely access to medical services when needed and that it also explores and recommends options for expanding the availability of specialist palliative care services for Queensland's aged-care homes.*⁴³⁵

Dr Nick Buckmaster, Medical Director General Medicine and Aged Care at Queensland Health told the committee:

*There are many points of failure in this system....one of those points of failure...is the waiting time for access to aged-care packages in the community. There is no question that delays in access for people with higher care needs particularly leads to at times unnecessary admission to either nursing homes or hospitals.*⁴³⁶

Mr Ian Landreth, Chief Executive Officer, Motor Neurone Disease Association of Queensland told the committee of a case involving a recently widowed woman who received the ACAT assessment for her late husband two weeks after he passed.⁴³⁷

⁴³² Submission 1891, p 42.

⁴³³ Submission 1309, p 4.

⁴³⁴ Submission 1212, p 1.

⁴³⁵ Public hearing transcript, Brisbane, 4 July 2019, p 66.

⁴³⁶ Public hearing transcript, Southport, 10 September 2019, p 3.

⁴³⁷ Public hearing transcript, Brisbane, 13 September 2019, p 4.

LASA informed the committee that its 3rd Home Care Provider Survey Report (March 2019) showed that wait-times are often much longer than those published on My Aged Care. Key issues identified by Home Care Providers in the survey included:

- 65 per cent of Home Care Package (HCP) providers indicated that the actual wait times of consumers on the national queue to be assigned a HCP were often between six and twelve months longer than those published on My Aged Care;
- 50 per cent of HCP providers also reported actual wait times as often being greater than twelve months longer than those published on My Aged Care;
- Many people on the queue never received the level of care that they were assessed as needing and instead passed away, or were exited from a HCP to hospital or residential care;⁴³⁸

Ms Joanne O'Shanesy told the story of her mother who had trouble accessing appropriate services in a timely manner:

*When Mum lived at home she was entitled to a 2-3 package, which gave us 6 hours of care a week. There are 168 hours in a week. I left for work each day at 6.30am and returned at 6.30 pm. She became assessed as a 3-4 package in 2017, but there were none available with her home care service. We literally had to wait for people to die to access the funds. As it was there was no capacity for overnight care or extended hours of care. Mum found it particularly stressful to go to out of home respite care, because of the combination of her blindness and her dementia.*⁴³⁹

CentaCareCQ advised that in Bundaberg at the time of their submission, they have 68 home care packages, but 115 clients on CHSP waiting to transition to home care packages or upgrade. In Rockhampton and Blackwater, they had 200 clients on CHSP waiting to transition to home care package or upgrade, but 113 home care packages, all filled. CentaCareCQ also provided the following examples to illustrate that waiting time are not meeting the needs of their clients.⁴⁴⁰

Table 10: Examples to illustrate waiting times

Date they entered list	Area	HCP Details	Time Waited	Expect Wait time (interim Package)	Expect Wait time full package	Priority
7/11/18	Bundaberg	Approved HCP2.	130 Days	1-3 Month (1)	9 – 12 Months (2)	Medium
31/01/19	Bundaberg	Approved HCP3	45 Days	3-6 Months (2)	12 Months+ (3)	Medium
30/11/18	Bundaberg	Approved HCP3	107 Days	12 Months+ (2)	12 Months+ (3)	Medium
23/05/18	Rockhampton	Approved HCP3	298 Days	6- 9 Months (2)	12 Months+ (3)	Medium
08/01/18	Rockhampton	Approved HCP3	433 Days	1-3 Month (2)	6- 9 Months (3)	Medium

Source: CentaCareCQ Submission 1297.

⁴³⁸ Submission 1283, p 3.

⁴³⁹ Submission 1791, p 3.

⁴⁴⁰ Submission 1297, p 3.

CentaCareCQ also provided the following examples for people waiting to transition to a higher care package.⁴⁴¹

Table 11: Examples for people waiting to transition to a higher care package

Date Entered Waitlist	Area	Current Interim Package	Committed Interim Date	Time waited for interim	Expect Wait time full package	Time Waited	Priority
22/05/18	Bundaberg	HCP (3)	1/02/19	255 Days	1-3 Month (4)	299 Days	High
01/06/18	Bundaberg	HCP (1)	9/01/19	222 Days	6- 9 Months (2)	289 Days	Medium
20/07/16	Rockhampton	HCP (3)	16/02/18	576 Days	3-6 Months (4)	970 Days	Not Known
17/02/17	Rockhampton	HCP (3)	02/11/18	623 Days	12 months + (4)	758 Days	Not Known
01/03/17	Rockhampton	HCP (3)	21/11/18	630 Days	12 months + (4)	746 Days	Medium

Source: CentaCareCQ Submission 1297.

HammondCare provided a further example of the wait for home care packages:

Compounding the problems clients face interacting with MAC is the shortage of home care packages, particularly Levels 3 and 4. Quarterly data released by the Australian Department of Health (DoH) suggest an individual approved for a Level 4 HCP can expect to wait 12-plus months for their package (DoH, 2019). In practice, wait times are often longer...HammondCare is well aware of the disparity between published estimations and actual waiting times. One Brisbane client was forced to wait 1,019 days (33 months) for a Level 4 package, receiving an interim Level 3 package more than a year (389 days) after first being approved for an HCP. Despite both timeframes indisputably not “meeting the needs of older Queenslanders”, such anecdotes remain unfortunately familiar in an era of Consumer-Directed Care (CDC).⁴⁴²

Submitters also stated that due to the long wait for home care packages, the needs of recipients have often increased during their wait time so that when they finally receive their package, it no longer meets their needs.

For example, Woombye Care submitted:

The new system with home care packages has led to ridiculous waiting lists which in turn prevents the elderly being able to access the care they require. It also means that by the time they receive the assistance they are initially assessed for they are already requiring more.⁴⁴³

Mr Colin Peake provided a personal example of the long wait his blind uncle had to endure:

At present, my experience has been, that elderly wishing to access the higher levels of the home care packages are often assessed poorly and have to wait too long. My elderly blind uncle, who had recently lost his wife was kept waiting too long before he was able to access a level 4 package. He had to be re assessed, after continual inquiries from his daughter, who is a nurse and then after requests to regional, state health care administration and finally politicians that action was finally taken. This is not how the process should work. There needs to more properly qualified assessors and more packages made available especially the level 3 and 4 so the waiting lists can be reduced.⁴⁴⁴

⁴⁴¹ Submission 1297, p 5.

⁴⁴² Submission 1261, p 5.

⁴⁴³ Submission 1254, p 1.

⁴⁴⁴ Submission E1850.

Ms Barbara Leadbetter, a business manager in the aged care industry told the committee at its Caloundra hearing of the passing of a client while waiting for a package upgrade:

*I look after home care packages in my role. ... I know of one man who died at home alone, waiting to have his package upgraded. We were only funded for two hours a week. He was palliative and he had been waiting 12 months. You can hear the agitation in my voice. I am very passionate about my industry and I am appalled at what the federal government is currently doing.*⁴⁴⁵

Mr Ross Musgrove, Chief Executive of the Western Downs Regional Council, highlighted the personal costs of package delays:

*I am advised that the waits are quite considerable and, in fact, some people pass away waiting for their package to be approved. There will always have to be a process in place, but it is important that that is expedited and suitable to address people's care at that time. With extended delays it is not just a period of time; it is a period of discomfort and the disruption that might be being caused within that family unit as well.*⁴⁴⁶

Adjunct Professor Edward Strivens from James Cook University and Clinical Director, Older Persons Sub-Acute and Rehabilitation at the Cairns and Hinterland Hospital and Health Service, highlighted the problems of package delays, the likelihood that lower level packages will be offered during the waiting period and the limited assistance provided to people in need of care under all package levels:

*...we have had problems with supply of home care packages. ... We are seeing waits of 12 months plus for level 4 packages, and that means that most people who are getting packages are actually getting the lower level—levels 1 or 2—prior to even getting a 3 or 4. Even when you consider a level 4 package of 18 to 20 hours a week, there are 24 hours in a day so you can see that really that is not necessarily going to be equivalent to the care you would receive in a facility without supplemental care from family members, friends or paid carers.*⁴⁴⁷

PCQ also expressed concerns about the lack of transparency on how the waiting list and priority allocation for home care packages operates:

*PCQ appreciates the competing priorities for people requiring a home care package and supports a single package assignment process which ensures equity of access. However, the time critical nature of the need for care for people with a life limiting illness with a short prognosis needs to be considered when assessing priority for access to a home care package.*⁴⁴⁸

Stakeholders also commented on the impact that the wait for home care packages has on the CHSP. For example, Cairns Community Legal Centre stated:

*...there is pressure, being placed on the Commonwealth Home Support Program (CHSP) to top-up the hours approved in the initial home care package...And while there has been an increase in the number of service providers since the introduction of the National Queue in February 2017, many of these providers only have approval to provide older persons with services allocated in the initial home care package, meaning that in some cases older persons are approved for higher levels of care but allocated lower levels and are unable to top-up their hours through CHSP.*⁴⁴⁹

Cairns Community Legal Centre suggested that as a result, greater pressure is put on carers, potentially leading to burn out, and perhaps elder abuse.⁴⁵⁰

⁴⁴⁵ Public hearing transcript, Caloundra, 3 May 2019, p 9.

⁴⁴⁶ Public hearing transcript, Toowoomba, 17 May 2019, p 4.

⁴⁴⁷ Public hearing transcript, Cairns, 27 May 2019, p 7.

⁴⁴⁸ Submission 1891, p 44.

⁴⁴⁹ Submission 1276, pp 1-2

⁴⁵⁰ Submission 1276, p 2.

Ms Leonie Synnes told the committee that the Australian Government has stopped service providers from being able to access CHSP services on top of their package ("grandfathering") in instances where a client has been given a lower level package than what they were approved for, limiting the appropriate and necessary care home care providers can give to their clients.⁴⁵¹

Queensland PHN's noted that efforts to top up using CHSP means the availability of this programme continues to decline, limiting its availability.⁴⁵²

PCQ told the committee:

*At 31 December 2018, there were 73,978 people who were awaiting their approved level package who had not yet been offered a lower level home care package. Of these people, 93.9 per cent (69,476) had been provided with an approval to access CHSP. However, CHSP is only designed to provide entry level support, which is well below the support most people with a life limiting illness and a short prognosis require. Yet, even when the services provided by CHSP would not be considered suitable, the Guidance on Priority for Home Care Services says 'if the client does not want to accept other interim services or informal / formal supports they should not be considered high priority' for a Home Care Package. Lack of clarity about eligibility for Commonwealth Home Support Program (CHSP), delayed access to home care packages (HCP) and limited funding available represent significant barriers for people with a life limiting illness in being able to access necessary services and choose where they received care as they near the end of their life.*⁴⁵³

Stakeholders called for the number of home care packages to be increased, via significantly higher funding, to reduce the wait for these packages, along with greater flexibility to move between packages.⁴⁵⁴ For example, the Queensland Policy Advisory Group of National Seniors Australia advised it has been calling for increased funding for high level home care packages and a tripling of level 3 and 4 home care packages to eliminate the waiting list for home care.⁴⁵⁵

Ms Suzanne Greenwood told the committee 'We all know the reality is that there are big waiting list and really funding is probably the underlying issue there'.⁴⁵⁶

ADA Australia stated that government investment in Home Care Packages is not meeting the current needs of older Australians and will struggle to meet future needs of Australia's growing ageing population if not addressed.⁴⁵⁷

Similarly, Brisbane South PHN raised a concern that announcements of funding for more packages at the higher levels may only keep pace with the growing number of older people and not completely provide for the backlog.⁴⁵⁸

The submission from AMA Queensland questioned whether home care providers could fulfil additional places in a timely manner if they were approved by the Australian Government, suggesting there is 'a systems mismatch and a systems funding issue which may lead to a systems failure if this is not corrected in the immediate future'.⁴⁵⁹

⁴⁵¹ Submission 212, p 2.

⁴⁵² Submission 1301, p 6.

⁴⁵³ Submission 1891, p 43.

⁴⁵⁴ See, for example, submissions 1201, 1243, 1297, 1304, 1309, 1400, 1891.

⁴⁵⁵ Submission 1309, p 2.

⁴⁵⁶ Public hearing transcript, Brisbane, 4 July 2019, p 77.

⁴⁵⁷ Submission 1243, p 3.

⁴⁵⁸ Submission 1212, p 2.

⁴⁵⁹ Submission 1233, p 1.

On the matter of the release of extra packages, SVHA noted the Australian Government released extra home care packages in 2018/2019 nationally, however:

- *the packages are not being released fast enough*
- *in some areas, it is difficult to support the implementation of the packages due to a lack of available and localised personal care/specialist aged care workforce*
- *funding does not extend to resolving underservicing in some areas. For example, it does not take into account the travel time of an organisation's staff to an individual's home.*⁴⁶⁰

Because of these impediments, SVHA believes there needs to be some adjustments to the contracting and funding conditions for service providers, to afford them an opportunity to better service, recruit and train an experienced aged care support workforce which can better support elderly people and those with special needs in aged care based in regional and rural Queensland.⁴⁶¹

The 3rd Home Care Provider Survey Report published by LASA (March 2019) also made recommendations regarding the release of packages, submitting:

- reducing Home Care Packages (HCP) wait times to no more than three months from the time of assessment to the time an older Australian receives support in their home
- limiting the level of unmet HCP demand, this phasing in of maximum wait times should be supplemented by prioritising the queue based on an individual's means and giving people the option of using their home equity to fund their care needs
- all unspent HCP funds returned to Government should be recycled into additional HCPs, and
- the Department of Health should publish clearer guidance for both providers and consumers on appropriate uses of HCP funds.⁴⁶²

Ms Jacqueline Williams suggested abolishing Level 1 funding, which she considers another type of CHSP service but at a greater cost to the consumer, and either allocating these funds to Level 3 / 4 home care packages or creating a Level 5.⁴⁶³

Mr Nicholas Delaney commented that the wait times are '...quite ridiculous when you consider the potential government savings in residential care that this could achieve with a resulting improved quality of care'.⁴⁶⁴

In order to reduce the queue and improve overall waiting times for home care consumers HammondCare offered the following solutions:

- Establish more home care packages, particularly higher Level (3 and 4 packages). One way to achieve this is to enable parked offline residential aged care licences to be converted to home care packages on a temporary basis, favouring high level packages (Tune Report Recommendation #6: That the government further increase access to high level home care packages to better reflect current demand by allowing for the temporary allocation of a home care package where there is a residential care place that is not being used).
- Reduce the period of time that consumers have to choose a provider and establish an agreement with them from 56 days (eight weeks) to 28 days (four weeks). Confident and capable consumers

⁴⁶⁰ Submission 1280, p 10.

⁴⁶¹ Submission 1280, pp 13-14.

⁴⁶² Submission 1283, p 5.

⁴⁶³ Submission E1693.

⁴⁶⁴ Submission 1354, p 1.

who have already been in the queue will have had sufficient opportunities to research and compare different providers.

- Like superannuation, clients who are unable to choose a service should instead be allocated a default provider. If a consumer has opted to engage a provider on their own but fails to activate their referral code within a set time period, then MAC should issue a public broadcast referral to all providers that provide home care packages in the consumer's location. This will activate a 'pull through' for those consumers who are at risk of missing out on the care they need, stopping them from falling through the gaps. However, consumers should maintain the option to change providers at any time. Utilising public broadcasts to pull clients through the system, along with a shorter choice period and a streamlined ability to change providers will ensure that no client falls through the gaps while continuing to uphold choice and helping to shorten the queue.⁴⁶⁵

The Royal Commission also heard many criticisms of waiting times for home care packages. In its interim report it stated:

*It is important to understand that the size and shape of aged care in Australia is constrained by the Australian Government through controls on the supply of aged care places, rather than being driven by demand. Understandably, waiting for aged care services that are in limited supply has become a focal point in criticism of the current system. The unclear measures of waiting and the need to wait for assessment, approval, allocation and service delivery has created a dysfunctional arrangement in which some people are waiting years to access services. Others wait long periods to receive less than what they need or, in some cases, nothing at all. This is clearly unsafe, especially as many die while waiting.*⁴⁶⁶

As noted above, the Royal Commission reported that more than 16,000 people died waiting for a Package on the national prioritisation queue during the 12 month period ending in June 2018, and that the mean waiting time for a Level 4 home care package in 2017-18 was 22 months.⁴⁶⁷ It further noted the lack of transparency in regards to progressing through the wait list:

*The Australian Department of Health, which oversees this system, has no mechanism to follow up with people who are on waiting lists to give them updates, including about whether they have progressed up the waiting list or how long it will be before a Package is available. In the interim, there is a clear and present danger of declining function, inappropriate hospitalisation, carer burnout and premature institutionalisation because necessary services are not provided. We have been alarmed to find that many people die while waiting for a Home Care Package. Others prematurely move into residential care.*⁴⁶⁸

6.4.2 Administration and delivery of in-home services

A range of issues in relation to the administration and delivery of in-home services were raised by stakeholders, including the transparency and accountability of fees, the ability to exercise choice, continuity and timing of services, and the quality of care.

According to ADA Australia, a lack of transparency in Home Care Package statements/invoices is one of the most common issues raised with advocates. ADA Australia submitted:

Without the provision of timely, transparent and easy to read statements/invoices, aged care consumers are unable to understand, plan or negotiate how their funds are spent. Advocates have also been involved in an increasing number of cases where clients have unknowingly been allowed to build up excessive debts within their package. For some, this has resulted in their

⁴⁶⁵ Submission 1261, p 5.

⁴⁶⁶ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 152.

⁴⁶⁷ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1,, p 154

⁴⁶⁸ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 3.

*services either being reduced or put on hold whilst funds are recouped. In many of these cases, debts were accumulated due to the complexity of statements and poor communication from service providers.*⁴⁶⁹

Concerns were also raised about the fees and charges charged by home care providers. ADA Australia submitted:

*...advocates report excessive case management, administration, brokerage and exit fees as an ongoing advocacy issue. The Commonwealth Government has done some work to address these concerns; requiring all service providers to publish their current Home Care pricing information on the My Aged Care (MAC) Service Finder and abolishing administration fees. However, ADA Australia has observed that service providers are now absorbing administration fees into other fees and charges such as direct care costs. ADA Australia also notes that there are many consumers without internet access who are not able to seek pricing information via the MAC website and are therefore unable to cross reference what they are being charged against the prices advertised and agreed to with the provider.*⁴⁷⁰

COTA Queensland referred to providers charging high administration costs, as well as in-home services often using subcontractors, which can increase the cost to the client.⁴⁷¹

Aged Care in Crisis submitted that the home care system and CDC are vulnerable to financial exploitation:

*... it is clear that many of those seeking to enter the sector and provide care are there for the money rather than the elderly. There are already examples and concern about overcharging. CDC also seems to have overheads in this system that see less of the money going to care. There is concern about both the approval process and the capacity to regulate using the current system.*⁴⁷²

Service provider interpretation of the types of services that can be provided under the home care package was also raised as an issue. Ms Lynette McLearie suggested that a common complaint relates to disagreements over what and how providers decide what they will and won't fund.⁴⁷³ She stated:

When funding is finally available the process of contacting, comparing and choosing a provider is a big task if unwell and without experience or appropriate help. Many are quite ill when they initiate this process and really would benefit from an advocate at that point.

Consultants working for the providers visit in person initially, list needs, and usually promptly fill some straight forward ones- house cleaning, lawn mowing, grocery shopping, food preparation. This tends to be an administrative roll.

*Beyond that, many battle with their providers. The broad guidelines obviously prioritise health and safety but interpretation of that is left to uncontactable people within organisations who correspond with clients via non decision-making staff and are not obliged to explain the how or why of their decisions.*⁴⁷⁴

ADA Australia referred to a lack of choice of services as part of the home care package, stating:

Consumers have expressed frustration in scenarios where service providers have not been able to provide a consumer with flexibility and choice, but the consumer is unable to seek care from

⁴⁶⁹ Submission 1243, p 3.

⁴⁷⁰ Submission 1243, p 3.

⁴⁷¹ Submission 1304, p 16.

⁴⁷² Submission 1227, attachment, p 9.

⁴⁷³ Submission 2562, pp 2-3.

⁴⁷⁴ Submission 2562, p 12.

*an alternative service provider because the impact of the over inflated exit fee would be too great.*⁴⁷⁵

Ms Catherine Brandon also raised the matter of flexibility, stating:

*The present “in home care” packages are worse than useless, there is not enough flexibility and too much money sitting in bank accounts not being able to be used for the client. Those agencies appear to be driven by how many clients they see not what sort of care they provide.*⁴⁷⁶

ADA Australia also raised the issue of access to aids and equipment, stating:

*Advocates have raised concern that it is becoming increasingly difficult to access equipment (mobility, ADL’s). In some cases, people have reduced necessary direct care services for a period so that they can accumulate funds to purchase necessary equipment.*⁴⁷⁷

Continuity of service for those receiving home care services, both in relation to who provides the service and the timing of the service, was raised by a range of stakeholders. For example, Ms Erika Gerdson referred to the need for some home care recipients to source services from different providers, submitting:

*If you’re at home, you may be getting different services from different providers (e.g. Personal Care, Respite, Domestic with one provider; Physiotherapy with another and so on.) In my experience there are many services whose books are closed and so you can’t necessarily get all services from the ONE service provider.*⁴⁷⁸

Queensland PHNs advised that discharge referrers from hospitals favour large organisations for services such as Nursing and Allied Health even when there are more culturally appropriate services available through other providers, meaning that:

*The lack of distribution of referrals to a range of providers means that it is difficult for the small to medium organisations to invest in their clinical services and staff e.g.: 7 days per week nursing. The result is that older people experience multiple organisations coming into their homes to provide various activities. Greater continuity and consistency would see one wrap around service.*⁴⁷⁹

Queensland PHNs also told the committee:

*Older people, their families and carers tell us that for in-home services delivered under the Commonwealth Home Support Program, they want consistency and continuity, i.e. they want to have the same care worker at the same time each week, and to have a say in how services are delivered. Variability across service providers is noted, for example some will provide a five-hour window for service delivery, while others will provide specificity of appointment times. It is commonly the large providers who only offer a time frame range.*⁴⁸⁰

Ms Jacqueline Williams noted the confusion that multiple service providers can cause for older people:

Since inception of MAC - there is a distinct lack of client continuity particularly in the CHSP funded arena. The assessment and allocation process via MAC has led to multiple different service providers being involved for individual CHSP clients. This is extremely confusing for the client and their families when the client then undergoes a form of ‘reassessment’ by the variety of different

⁴⁷⁵ Submission 1243, p 3.

⁴⁷⁶ Submission 2403, p 1.

⁴⁷⁷ Submission 1243, p 3.

⁴⁷⁸ Submission 1642, p 6.

⁴⁷⁹ Submission 1301, p 4.

⁴⁸⁰ Submission 1301, p 4.

*organisations supplying the services; multiple documents / charts / careplans in the client's home; multiple invoices (client co-contributions) due to the variety of service providers.*⁴⁸¹

HammondCare advised that its bi-annual 'Partnering in Care' surveys have highlighted an ongoing theme of consumers valuing staff consistency, which it has acted on by reducing reliance on agency staff in its services.⁴⁸²

COTA Queensland stated that the scheduling of services can be difficult, with scheduling based on the priorities of the service provider not on the needs of the client.⁴⁸³ Ms Lynette McLearnie referred to 'chaotic rostering of services'.⁴⁸⁴

Ms McLearnie also submitted that another common complaint is a large staff turnover within organisations, while COTA Queensland advised staff shortages mean that consumers' care provider changes.⁴⁸⁵

The ability for people to access home care in regional and rural areas was also raised by submitters. COTA Queensland told the committee that consumers in rural and regional Queensland often lack choice in providers.⁴⁸⁶

Ms Lenore Keough also raised this issue, submitting:

*Another issue we've become aware of is the limited services available in a rural location (this may be true everywhere, but certainly true in my mother's location). Suppliers for services my mother needs under the interim support arrangements mentioned above are not available (i.e. the suppliers have 'closed their books' and many of them don't even offer a waiting list).*⁴⁸⁷

QLS noted there are generally longer waiting periods in regional and remote areas, than cities, particularly for level 3 and 4 packages.⁴⁸⁸

Some submitters told the committee about the difficulties service providers face in delivering their programs in terms of competition, funding and the wait for home care packages. Queensland PHNs explained that:

*...service providers tell us that as in-home care providers, they have a lack of flexibility within program structures to allow them to adapt to meet consumer expectations, i.e. being flexible with funding across activities. Greater flexibility would also make transition from hospital and other services smoother as well and better accommodate changing needs over short periods of time.*⁴⁸⁹

...

*Meanwhile for service providers delivering Home Care Packages, there is increased tension between consumer choice and competition for services, which puts commercial pressure on providers to balance client acuity and complexity, waiting lists, unspent funds and client preferences.*⁴⁹⁰

⁴⁸¹ Submission E1693.

⁴⁸² Submission 1261, p 6.

⁴⁸³ Submission 1304, p 16.

⁴⁸⁴ Submission 2562, pp 2-3.

⁴⁸⁵ Submission 2562, pp 2-3; 1304, p 16.

⁴⁸⁶ Submission 1304, p 15.

⁴⁸⁷ Submission E1741.

⁴⁸⁸ Submission 1201, p 7.

⁴⁸⁹ Submission 1301, p 2.

⁴⁹⁰ Submission 1301, p 3.

Woombye Care also commented that providers are struggling to make ends meet because of the changes to the funding model, with some providers ceasing the community care side of business because it isn't viable.⁴⁹¹

Queensland PHNs also commented on the difficulties faced by service providers in relation to workloads:

*Longstanding, large community care service providers, who to date have absorbed the impact CHSP funding limitations and long HCP wait lists, are now in financial deficit and have put all new community nursing admissions on hold, stating 'lack of capacity', increasing the demand on other community service providers who do not have adequate staffing levels and increasing therefore avoidable presentations to ED [emergency department].*⁴⁹²

The QNMU referred to its members reporting unreasonable workloads trying to meet consumer needs and expectations, while COTA Queensland advised feedback they have received indicates staff are given minimal time to undertake tasks, leaving little or no time for personal interaction.⁴⁹³

Some submitters raised the issue of the skill set of home care providers. The QNMU submitted:

While the current ANMF Ratios for Aged Care Campaign is focused on the residential aged care setting, feedback from members, numerous reports in recent years and the ongoing Aged Care Royal Commission indicate staffing and skill-mix deficits occur across the sector.

*The deskilling of the aged care workforce is not confined to the residential sector. High workloads, short-staffing, unrealistic schedules and the added supervisory burden required for RNs to supervise a dispersed community aged care workforce are all reported by QNMU members. It is essential the same evidenced based approach to staffing and skill-mix be supported by research in the community setting.*⁴⁹⁴

Similarly, the QLS expressed the view that the quality of care received and the quality of the staff is dependent on the service provider and that there are insufficient regulated requirements for staff training, or qualifications.⁴⁹⁵

COTA Queensland advised that in their survey of aged care stakeholders, participants suggested that providers are focused on making money ahead of providing care, and that staff may not be trained to notice signs of physical or cognitive decline (decline indicating that services need to be reviewed).⁴⁹⁶

LASA told the committee there is also widespread concern among providers about inappropriate HCP expenditure requests from consumers.⁴⁹⁷

Concerns regarding the potential for elder abuse were also raised. Ms Erika Gerdson submitted:

*Care in one's own home means a person is may [sic] more vulnerable to abuse as there is less supervision as to what's going on behind closed doors.*⁴⁹⁸

Ms Jacqueline Williams commented:

Elder abuse in residential is mandatory reporting. In home care settings it is not. It is up to the organisation to have in place robust policy and procedures for elder abuse in the community.

⁴⁹¹ Submission 1254, p 1.

⁴⁹² Submission 1301, p 4.

⁴⁹³ Submission 1213, p 14; 1304, p 16.

⁴⁹⁴ Submission 1213, p 17.

⁴⁹⁵ Submission 1201, p 5.

⁴⁹⁶ Submission 1304, p 16.

⁴⁹⁷ Submission 1283, p 3.

⁴⁹⁸ Submission 1642, p 2.

*Many organisations consider elder abuse as a critical incident (which it is) but it is not mandatorily reported externally like it is in residential care. This is a significant flaw in our system and we are letting down some of our most vulnerable community.*⁴⁹⁹

6.4.3 Adequacy of package

Some submitters questioned the adequacy of the home care package to meet the aged care needs of older people. For example, the QLS suggested that home care packages generally meet the aged care needs for an adult commencing in Level 1 or 2, however Level 3 and 4 packages often do not meet the real needs of the adult, such as nursing support services.⁵⁰⁰

Ms Deborah Frugtniet told the story of how her father was put into an RACF because of the inadequacy of the help available to them:

Mum cared for dad as long as she possibly could in their home. They moved closer to medical services to make it easier for both of them and to be closer to us, their kids.

*Unfortunately, nine months ago dad was deemed far too much for mum to care for at home and that is because, in our belief, the in-home services are just not adequate. Mum was firstly put through a rigmarole of invasion of privacy and made to feel like she had to answer for things that she should not have just to get the care. Dad is a gold card holder. As I said, he fought for our country and has been an upstanding citizen for his 80 years, mum also. The first thing we saw was the rigmarole mum was put through. I can imagine how a person of 70 years of age, if she did not have the support of her kids and grandkids around her, might struggle with that or how that might challenge them and I fear for those other elderly people who are standing on their own because, honestly, that is our first issue—that is, the problems that they have been put through to get the help. Then there is the issue of not being able to care for him in their home because the help is just not adequate and having to take dad and put him in a care facility.*⁵⁰¹

The LCAQD indicated that there is currently ‘a great divide’ between the Level 4 Home Care Package and full-time residential aged care, creating risk for older persons living at home who require more than 12 to 15 hours of support per week. LCAQD suggested that as a result of this divide, these individuals can become increasingly frail, putting them at greater risk of falls and hospitalisation due to preventable injuries and wider issues of frailty.⁵⁰²

Ms Erika Gerdson commented that aged care for people still living at home results in an over reliance on a person’s family to provide support, and states that family carers are extremely undervalued.⁵⁰³

Committee comment

In evidence to the Royal Commission, it was revealed that 127,000 people were waiting for their approved home care packages. For level 4 packages, the highest level of assistance for people with high care needs, the waiting period has been reported as 22 months. The committee heard of instances where people have waited even longer.

Many thousands of people have died while waiting for their home care packages. It was reported to the Royal Commission that 16,000 people died waiting for their approved package during one year, 2017-18. Many others occupy acute care beds in hospitals while waiting for a package to return to their homes. This imposes significant costs on the State’s public health system in terms of direct clinical

⁴⁹⁹ Submission E1693.

⁵⁰⁰ Submission 1201, p 5.

⁵⁰¹ Public hearing transcript, Southport, 10 September 2019, p 44.

⁵⁰² Submission 1277, p 4.

⁵⁰³ Submission 1642, p 2.

and other costs, as well as on their ability to care for other patients. Others have moved to residential aged care against their wishes and the wishes of their families.

Such delays in providing care would not be permitted in a health service environment and are simply unacceptable in aged care. In some cases the care needs of the package recipient has increased while waiting for a package, and the package provided no longer meets their needs. The extended waiting periods for packages also impose extraordinary burdens on the informal carers who are caring for those people.

These statistics are a damning indictment of the failures of the Australian Government's home care package program. The program needs to be significantly better resourced to increase the numbers of packages that are available, particularly for the higher level 3 and 4 packages. It is also imperative that the Australian Government commits to limiting the unmet demand for home care packages, and to adopting maximum waiting times for packages to be allocated. Three months has been suggested to the Royal Commission by the Council of the Ageing and Leading Aged Services Australia as a reasonable maximum wait period.⁵⁰⁴ Whatever waiting period is accepted, it is essential that the Government commits to providing interim care arrangements, equivalent to the level of care approved, for applicants from the time a package is approved until it is provided.

Further issues were raised about the adequacy of the amounts provided for packages, the fees charged for administering home care packages, the difficulties for package recipients in exercising choice, the timing of care services, the quality of care provided and the training received by care staff.

Stakeholders also raised concerns that elder abuse detected during in-home care may not be reported to the same extent as abuse in a residential care setting.

Recommendation 10 Increased funding for the Home Care Packages Program

The committee recommends that the Australian Government significantly increase the level of funding it provides to the Home Care Packages Program to ensure packages are sufficient to meet the costs of the required hours of care required for each level package, to clear the current backlog of packages that haven't been provided.

Recommendation 11 Removal of caps on Home Care Packages

The committee recommends that the Australian Government remove its cap on the number of packages available, at all levels, and provides as many packages as are needed.

Recommendation 12 Clearing of backlog in Home Care Packages that have not provided

The committee recommends that the Australian Government clear the current backlog of packages that haven't been provided.

Recommendation 13 Maximum waiting times for Home Care Packages

The committee recommends that the Australian Government ensure wait times for packages are reduced to a maximum of three months for delivery of all packages across all levels from the date of approval.

Recommendation 14 Access to interim care while waiting for Home Care Packages

The committee recommends that the Australian Government commit to provide interim care arrangements, close to the approved package level, for applicants for home care packages while waiting for their package to be provided.

⁵⁰⁴ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 162, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

Recommendation 15 Mandatory reporting by home care staff of elder abuse

The committee recommends that the Australian Government requires that the reporting of elder abuse is a mandatory requirement for all staff working in home care.

Recommendation 16 Qualifications and training for personal carers providing in-home aged care

The committee recommends that the Australian Government consider whether there should be mandatory minimum qualifications and training for personal carers providing in-home aged care.

7 Residential Aged Care

7.1 Overview

Residential aged care provides support and accommodation for people who have been assessed as needing higher levels of care than can be provided in the home, sometimes requiring 24-hour nursing care, and therefore can no longer remain living independently at home. Residential care is provided on a permanent or respite basis.⁵⁰⁵

The services provided through residential aged care include support with day-to-day tasks, personal care, clinical care such as medication administration and management, accommodation services, and other care services. For people who need almost complete assistance with most activities of daily living, residential aged care can provide 24-hour care.⁵⁰⁶

Providers of residential aged care services must first be approved by the Australian Government, in accordance with the Aged Care Act, before providing care delivery. Providers comprise those from religious, charitable, community, for-profit and government sectors.

Nationally, in 2017–18, the majority of people entering permanent residential aged care were aged 75 years and over (85 per cent), and just under 4 per cent of entries were people aged under 65 years. In 2008–09, people aged 85 years and over made up 49 per cent of entries to permanent residential care. In 2017–18, this proportion had increased to 53 per cent.⁵⁰⁷ In 2018–19, the average age on admission to permanent residential aged care was 82.3 years for men and 84.6 years for women.⁵⁰⁸

7.2 Funding

The cost of residential aged care is met by both public (Australian Government) and private (individual) funding, which is used to support operational funding and capital financing. Operational funding supports day-to-day services such as nursing and personal care, living expenses and accommodation expenses. Capital financing supports the construction of new residential care facilities and the refurbishment of existing facilities.⁵⁰⁹

The arrangements for funding are set out in the Aged Care Act or in the *Transitional Provisions*, with some of the arrangements differing depending on when a person entered care.

7.2.1 Operational funding

A combination of Australian Government and resident contributions provides the operational funding for residential care.

The Australian Government determines its contributions on behalf of permanent residents in residential care by setting:

⁵⁰⁵ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 12; Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 2, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁵⁰⁶ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 12.

⁵⁰⁷ Australian Institute of Health and Welfare, GEN Aged Care Data, Explore admissions into aged care, <https://www.gen-agedcaredata.gov.au/Topics/Admissions-into-aged-care/Explore-admissions-into-aged-care>.

⁵⁰⁸ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 15, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁵⁰⁹ Aged Care Financing Authority, Seventh report on the Funding and Financing of the Aged Care Industry 2019, p 91, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

- a basic care subsidy for personal and nursing care
- the rates of supplements paid to support aspects of residential care that incur higher costs to deliver, and
- the maximum rate of accommodation supplement.

The Australian Government also sets the maximum levels for contributions made by residents for the following:

- the maximum rate of the basic daily fee for living expenses (permanent and respite), and
- the maximum means tested care fee that may be charged by providers (permanent only).⁵¹⁰

7.2.2 Capital grants

Under the Australian Government funding framework for residential aged care, it is the responsibility of the approved provider to meet the costs associated with the development, construction, maintenance and upgrade of aged care services.⁵¹¹

Some financial assistance in the form of residential care grants under the Aged Care Act (capital grants) is available to aged care providers. Capital grants are provided for the construction or upgrade of residential care buildings:

- in rural, regional and remote areas, and/or
- which specifically focus on the provision of residential care to people from Special Needs Groups or concessional, supported, assisted or low-means residents, including in major cities.⁵¹²

Providers are able to apply for capital grants through the Aged Care Approvals Round (ACAR). This is a competitive assessment process.⁵¹³

7.2.3 Payments and subsidies

The majority of Government funding is made up of the basic subsidy which, for permanent residential care, is determined through the appraised care-needs of a resident by applying the Aged Care Funding Instrument (ACFI). The ACFI consists of questions about assessed care needs, some of which are supported by specified assessment tools and two diagnostic sections. The ACFI consists of 12 questions which are rated by the aged care home on a scale of A, B, C, or D then used to determine an individual's ACFI score. In addition to the subsidy determined by the ACFI, supplements may be payable.⁵¹⁴ ACFI is self-assessed by providers, but is subject to audits by the Department of Health.⁵¹⁵

⁵¹⁰ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 92, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵¹¹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 15.

⁵¹² Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 15.

⁵¹³ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 15.

⁵¹⁴ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, pp 33-34, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁵¹⁵ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 93, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

Table 12: Supplements available for residential aged care 2017–18

Supplement Type	Description
Primary supplements	
Respite supplement	A supplement paid to residential care services for provision of residential respite care to eligible care recipients who normally live in the community.
Oxygen supplement	A supplement paid to residential care services on behalf of eligible care recipients to reimburse costs associated with providing oxygen therapy.
Enteral feeding supplement	A supplement paid to residential care services on behalf of eligible care recipients to reimburse costs associated with providing enteral feeding.
Other supplements	
Accommodation supplement	A means-tested supplement paid to residential care services on behalf of care recipients who entered care on or after 20 March 2008 who are eligible for assistance with their accommodation costs.
Hardship supplement	A supplement paid on behalf of care recipients in financial hard ship who are unable to pay their aged care costs.
The Veterans' supplement in residential care	A supplement paid on behalf of residents with a mental health condition related to their service. Eligibility for the supplement is determined by the Department of Veterans' Affairs.
Viability supplement	A supplement paid to aged care services in rural and remote locations to assist with the extra cost of delivering services in those locations.
Homeless supplement	A supplement paid to aged care services that specialise in caring for people with a history of, or who are at risk of, homelessness.
Concessional supplement	A means-tested supplement paid on behalf of concessional and assisted residents who entered residential care between 1 October 1997 and 19 March 2008 who are eligible for assistance with their accommodation costs.
Transitional supplement	A supplement paid on behalf of pre-2008 reform care recipients who were residents in an aged care home on 30 September 1997 or who entered the service after 30 September 1997 but before it was certified, and who have remained in the same home.
Charge exempt supplement	A supplement paid on behalf of residents who were in high care on 30 September 1997 and who have subsequently moved to another home where they would be eligible to pay an accommodation charge.
Transitional accommodation supplement	A supplement paid on behalf of residents who entered low level care between 20 March 2008 and 19 September 2011, to ensure no financial disadvantage from changes to the accommodation supplement which was introduced on 20 September 2011.
Accommodation charge top-up supplement	A supplement paid on behalf of high care residents who entered care from 20 March 2008 to 19 March 2010 and who were on income support.
Basic daily fee supplement	A supplement paid on behalf of certain care recipients in permanent care on 1 July 2012 to ensure no financial disadvantage resulting from the increase of the basic daily fee from that date.
Pensioner supplement	A supplement payable for pre-March 2008 reform residents who either have a dependent child or receive an income support payment and have not agreed to pay a "big bond". ⁵¹⁶

Source: Australian Government, Department of Health, 2018–19 Report on the Operation of the Aged Care Act 1997, pp 47-48.

⁵¹⁶ Australian Government, Department of Health, Supplements for residential aged care, <https://www.health.gov.au/initiatives-and-programs/residential-aged-care/funding-for-residential-aged-care/supplements-for-residential-aged-care>

Depending on their income and assets, residents may be asked to make a contribution to their accommodation costs. The table below outlines these fees and payments.

Table 13: Fees and payments that may be required of residents

Contribution	Description
Fees	
Basic daily fee	All residents in aged care homes can be asked to pay a basic daily fee (standard resident contribution), which equates to 85 per cent of the single rate of the basic age pension. This fee is used by the approved provider to cover costs such as cleaning, maintenance and laundry. The basic daily fee is indexed on 20 March and 20 September each year, at the same time as changes to the age pension.
Means-tested care fee	Means-tested care fees are calculated based on an assessment of the resident's income and assets. Significant safeguards, including annual and lifetime caps on the means-tested care fees payable by residents, apply to the post 1 July 2014 fee arrangements to limit the amount a person can be asked to pay.
Extra service fees	The extra service fee is the maximum amount a provider can charge a resident for receiving extra service in a residential care home which has been approved for extra service status. Extra service status in residential aged care involves the provision of additional hotel-type services, including a higher standard of accommodation, food and services than the average provided by residential aged care homes which do not have extra service status.
Additional service fees	An approved provider may also charge a resident for additional services (e.g. hairdressing), which the resident has asked the provider to provide. The amount of any charge for additional services must be agreed with the resident before services are delivered, with an itemised account given to the resident once the service has been provided. Fees for other care or services cannot be charged unless the resident receives direct benefit or has the capacity to take up or make use of the services
Payments	
Accommodation payments	Accommodation payments are a contribution to the cost of accommodation and are used to maintain and upgrade the aged care facility. Accommodation payments are means-tested. Some residents pay an accommodation contribution, with the Australian Government paying the remainder. Those residents with higher levels of income/ assets, are required to pay the full cost of their accommodation through an accommodation payment which is negotiated with the provider. Australian Government contributions towards accommodation costs are by way of accommodation supplements. Providers determine the maximum prices they wish to charge for their accommodation (for residents who do not receive any government assistance with the cost of their accommodation) and publish these prices, along with information about the key features of the room, on My Aged Care, on their own website and in their printed materials.

Source: Australian Government, Department of Health, 2018–19 Report on the Operation of the Aged Care Act 1997, pp 50-51.

The Minister determines the rates for subsidies and care-supplements to be paid from 1 July each year, and the rates of accommodation-linked supplements on 20 March and 20 September each year. The

current rates of payment for subsidies and supplements are available on the Schedule of Subsidies and Supplements on the department's website, and from My Aged Care.

The Australian Government also supports access to permanent residential care by consumers who are assessed as not being able to meet all or part of their own accommodation costs. Providers are paid an accommodation supplement on behalf of these residents who are referred to as supported (or low-means) residents. Eligibility for a full or partial accommodation supplement is determined by a combined assessment of an individual's income and assets (the means test). Providers have discretion to determine the proportion of supported residents in their facilities. However providers with 40 per cent or fewer supported residents in a facility (excluding those residents receiving extra services) have the accommodation supplement they receive for all supported residents in that facility reduced by 25 per cent.⁵¹⁷

7.2.4 Proposal for a new residential aged care funding model

Since 2017 the Australian Government has been examining options for a new funding tool and system to replace the current ACFI.

The Government commissioned a study on the relative costs of providing care for residents with differing care needs and has been consulting with the sector on long-term reform options for residential aged care funding.⁵¹⁸ The department engaged the University of Wollongong to undertake a Resource Utilisation and Classification Study (RUCS). The purpose of this study was to determine the characteristics of residents that drive residential care costs, and use this information to inform the government's consideration of future reform options. The RUCS was completed in December 2018.⁵¹⁹ Reports from the RUCS were released in March 2019 and include evidence on the drivers of costs of care in residential care facilities as well as a proposed new funding model to replace the ACFI. The Government is consulting with the sector on the recommendations in the reports.⁵²⁰

The RUCS suggests that ACFI does not adequately distinguish between the fixed costs of providing residential aged care and the variable costs per resident based on individual care needs.⁵²¹ The Australian Health Services Research Institute at the University of Wollongong has recommended a new model and funding system, referred to as the Australian National – Aged Care Classification, which is designed to deliver more stable funding arrangements. Consultation seeking feedback and views from the residential aged care sector and broader community on the Australian National – Aged Care Classification closed on 31 May 2019.⁵²²

⁵¹⁷ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 50, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵¹⁸ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 94, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵¹⁹ Australian Government, Department of Health, Resource Utilisation and Classification Study (RUCS) Reports, <https://www.health.gov.au/resources/publications/resource-utilisation-and-classification-study-rucs-reports>.

⁵²⁰ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 94, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵²¹ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 94, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵²² Australian Government, Department of Health, Proposal for a new residential aged care funding model, Consultation Paper, p 5, <https://agedcare.health.gov.au/reform/residential-aged-care-reform>.

The Australian Government announced a trial on 10 February 2019 as part of a \$662 million aged care package to support older Australians. The purpose of the trial is to:

- field test the assessment tool and supporting software, hardware, IT systems and IT support arrangements, and assessment workforce management processes, to ensure suitability of the RUCS model for national implementation, and
- validate the RUCS model's findings about the expected distribution of care recipient classifications.

This may be welcome news for RACF providers, the majority of whom, according to ACFA have:

...indicated that their financial performance had deteriorated in 2017-18 and a number said they were moving into a loss situation. The results from the 2017-18 Aged Care Financial Reports, which are supplied by all providers and is the basis for ACFA's 2019 annual report, confirms that 2017-18 was a difficult year for aged care providers.

*The average Earnings Before Interest, Tax, Depreciation and Amortisation (EBITDA) per resident for residential care providers had improved each year for five years since 2012-13. In 2017-18, however, it fell by 24 per cent, and 44 per cent of residential care providers reported a loss compared with 32 per cent in 2016-17. There was a very significant decline in the financial performance of regional residential care providers in 2017-18 and, on average the performance of not-for-profit providers dropped significantly more than for-profit providers.*⁵²³

The decline in the performance of residential care providers is seen as partly due to the Government's changes to the ACFI that took effect in 2016 and 2017 and the pause in ACFI indexation in 2017-18. With ACFI revenue contributing over 60 per cent of the revenue of residential care providers, ACFA states:

...the changes to ACFI considerably constrained providers' revenue while their costs, particularly staff costs, continued to rise. In 2017-18, the expenses of residential care providers increased by 5.3 per cent while their income increased by 1.7 per cent.

...

*Feedback from consultations with residential care providers suggests the financial pressures they experienced in 2017-18 have continued into 2018-19. Providers note that while the pause in ACFI indexation has ended, the indexation rate in 2018-19 (1.4 per cent for the activities of daily living and behaviour domains and 0.7 per cent for complex health) is below the rate of increase in their costs.*⁵²⁴

7.2.5 Issues with residential aged care facility funding

Stakeholders raised issues with the funding model for RACFs, commenting on how funds are determined and the lack of transparency and governance on how those funds are spent, as well as the cost to residents to access a place in an RACF.

7.2.5.1 Funding and flexibility of residential aged care facilities

As mentioned in section 4.1, a number of stakeholders expressed the view that the current level of funding of aged care services is inadequate. However, stakeholders also raised issues with the current funding model specific to RACFs.

⁵²³ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p ix, <https://www.health.gov.au/sites/default/files/documents/2019/11/seventh-report-on-the-funding-and-financing-of-the-aged-care-industry-july-2019.pdf>.

⁵²⁴ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p ix, <https://www.health.gov.au/sites/default/files/documents/2019/11/seventh-report-on-the-funding-and-financing-of-the-aged-care-industry-july-2019.pdf>.

One of the issues raised by stakeholders was the method by which the ACFI awards funding based on level of need, potentially impacting on an older person's ability to access a place in an RACF or receive the health that they require. For example, Cancer Council Qld submitted:

*In part, we observe that funding mechanisms can contribute to consumers' (in)ability to access appropriate aged care services. Some nursing home facilities will only admit patients based on their clinical need. If the clinical need is not high enough to fit it the highest earning Aged Care Funding Instrument (ACFI) claim, nursing home administration may turn away patients.*⁵²⁵

Woombye Care referred to the lack of incentive to rehabilitate a patient, advising:

*Currently the residential care funding model works on you receiving more money the more debilitated the person is, this doesn't give facilities much motivation to spend the time rehabilitating a resident after they have had an acute event such as a fall, fracture, cardiac event. Many facilities have an attitude that residents are easier to look after if they are immobile and ACFI supports this attitude.*⁵²⁶

Mr Choe Lam Tan, Founder and Managing Director of Jeta Gardens in Bethania, Brisbane, told the committee:

*... I think there is a fundamental flaw in the way the funding of the government is implemented. The whole objective for us as a service provider is to be able to give the best service, so that the receiving end—the residents—will be healthier and happier. That is the outcome that we want: they are better in wellbeing and everything. However, the funding is in the reverse. If we do well and he gets better, the funding gets less. The funding gets less because the funding depends on how the level of care is acquired. The better you do, many times you get less money, so you remove the incentive or motivation for people, apart from those with a big heart. It just becomes a commercial organisation. The ones who do the best have the funding cut. That is a fundamental flaw. It should be the reverse. If you do better and are able to discharge everyone home, you should be a good person and get paid for doing such a good job. I think there is a fundamental flaw there.*⁵²⁷

Queensland PHN submitted that the ACFI has not supported adequate clinical care provision and stated 'the Resource Utilisation Classification Study makes recommendations to move to a better system'.⁵²⁸

Mr Ross Pitt submitted that the financial pressure from the Commonwealth Government on nursing homes to take only high care and very high care residents is exacerbating the problem of bed blocking in the acute care system. He stated:

*The average length of stay in a nursing home has gone down rapidly from an average of around twelve months to somewhere between 7 and 8 months across the public, private, and not-for-profit aged care providers. But the average length of stay for "bed blockers" in the acute care setting, who are not classed as high care, is blowing out. Those stranded in the acute care setting are at high risk of falls and other adverse incidents. This is clear from the Adverse Incidents figures.*⁵²⁹

Woombye Care advised there is nothing mandated about how facilities must spend the money they receive for ACFI claims, stating:

⁵²⁵ Submission 1303, attachment, p 1.

⁵²⁶ Submission 1254, p 3.

⁵²⁷ Public hearing transcript, Brisbane, 18 October 2019, pp 8-9.

⁵²⁸ Submission 1301, p 3.

⁵²⁹ Submission 471, p 2.

*A facility should be using most of that to provide direct care to the residents, not paying shareholders. The government also needs to assess the 24 hour care that we provide to residents and the daily payment we receive for that in comparison to what a hospital receives. We are expected to provide somewhat of the same care to people with a huge difference in funding.*⁵³⁰

The National Seniors Australia Policy Advisory Group similarly raised accountability for funding as an issue, stating:

*Residential aged facilities receive extra funding for people with higher needs. Residents who are very frail or suffer dementia, for example, require greater nursing care than a resident with low care needs to support activities of daily living, including feeding, dressing, bathing and toileting. However, there is no requirement to demonstrate that any extra money received for an individual's care be used for their individual care. Providers need only meet the standards of care set out in the quality standards.*⁵³¹

Submitters suggested that some RACFs, particularly for-profit providers, are more focused on, or at least conflicted by, the goal of making a profit in an industry based on care for the elderly, and therefore may not provide an appropriate level of care to residents in pursuit of that profit.⁵³² For example, Mr Nicholas Delaney stated that:

*The for profit services are generally in a very conflicted situation where they do not have the funding to provide adequate services as well as a reasonable return to investors. Generally the not for profit providers do a better job at of [sic] providing a good service at moderate cost.*⁵³³

Ms Linda Mungomery similarly submitted:

*The care providers interests are foremost - their profits and organisational culture limit their ability to provide responsive quality care. The only benefit I see after changes to care provider systems has been giving the consumer [family] the right to refuse a particular carer if they are not happy with their care.*⁵³⁴

...

*I think the public system does a better job at managing health services than private entities including charitable and not-for-profits. Some smaller community based nursing homes I have found to be more likely to be person centred in their approach and their overall philosophy. Without the financial goals of profits for share holders, CEO and Executive bonuses, priority can be given to actual care. Paying directly to those who provide the care - nurses, carers, allied health, domestic and catering staff and activities that meets their special needs.*⁵³⁵

Ms Lynne Ferguson suggested that 'aged care should be retrieved from the private sector, or much more stringent staff / patient ratios must be enforced, with much better compulsory training standards for ALL staff in working with the elderly, particularly the frail and those suffering dementia'.⁵³⁶ Dr S D'Urso called for a total exclusion of private for-profit providers, stating that sectional interests are incompatible with the common good especially vulnerable aged people.⁵³⁷

Suggestions to address these problems included:

⁵³⁰ Submission 1254, pp 2-3.

⁵³¹ Submission 1309, p 4.

⁵³² See, for example, submissions 1354, 1370, 1445, 2057.

⁵³³ Submission 1354, p 2.

⁵³⁴ Submission 1370, p 1.

⁵³⁵ Submission 1370, p 3.

⁵³⁶ Submission 252.

⁵³⁷ Submission 310, p 1.

- more scrutiny of providers to ensure funding is being spent on proper care, not going to increased profits⁵³⁸
- developing a funding model that has greater flexibility to meet care needs with incentives for providing quality care based on meaningful indicators,⁵³⁹ and
- shifting control over residential care funding to residents and their families (rather than the current system that allocates ‘bed licences’ to providers).⁵⁴⁰

The Royal Commission heard similar concerns about funding. In its interim report it noted a lack of transparency regarding the use of funds by RACFs and stated ‘There is no public information on the way providers use taxpayers’ funds and individuals’ contributions to deliver aged care services’.⁵⁴¹

The LCAQD raised the issue of funding for capital works, particularly for not for-profit organisations, submitting their RACFs:

...have high levels of concessional residents those who are unable to pay for their accommodation deposits or contributions in our aged care services. At some of our sites, up to 70 per cent are concessional residents.

Also, as a result of this, Lutheran Services has much smaller pools of working capital via Refundable Accommodation Deposits (RADs) to invest in infrastructure and technological upgrades. This often results in slower upgrades and improvements.

We would see merit in the offering of grants or low interest loans to not-for-profit organisations to deliver the most contemporary infrastructure options to those who cannot afford to pay upfront accommodation deposits. Many rural people (even if they are housing owners) have lower or insufficient equity to pay upfront accommodation deposits due to low median house values in these communities. This necessitates our organisation to borrow funds commercially to build new infrastructure.⁵⁴²

7.2.5.2 Cost to residents

The cost to access RACFs, particularly for those on low incomes, was an issue raised by a number of stakeholders.⁵⁴³ The profits made by RACFs was also canvassed.⁵⁴⁴

For example, COTA Queensland told the committee:

In 2017-18, approximately 47 per cent of Queensland’s residential aged care residents depended on Australian Government subsidies to fund their access to residential care. This is higher than the national average of 43.4 per cent receiving government subsidy.

The Australian Government subsidises residential aged care based through a means test. All aged care users are expected to contribute to the cost of providing their service. The number of subsidised places in Queensland has fallen in recent years. It is possible that consumer demand may have fallen. However, current wait times for care ... suggest that this is not likely to be the case.

A residential care provider receives up to 85 per cent of an individual’s pension as a contribution towards care costs. This means that a person in subsidised residential aged care receives just

⁵³⁸ Mr Robert Wilson, submission 444, p 1.

⁵³⁹ Queensland PHNs, submission 1212, p 5.

⁵⁴⁰ COTA QLD, submission 1304, p 10.

⁵⁴¹ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 132.

⁵⁴² Submission 1277, p 3.

⁵⁴³ See, for example, submissions E300, 297, 1207, 1254.

⁵⁴⁴ See for example, submissions E543, 1254.

\$207 per fortnight for their living expenses (based on a pension with allowances of \$916 per fortnight). While it's clear that residents in aged care have low living expenses because their care needs are provided, it's possible that this low income limits the possibilities available to people in residential aged care, who may find themselves unable to afford simple interactions with their community and simple services such as a telephone.

Low incomes are a concern for many older Queenslanders, which influence their access to care and support outside the aged care sector. Important issues include the cost of health care, transport, housing and related costs such as utilities, and having sufficient spare funds to support active participation in their local community.⁵⁴⁵

The Cancer Council Qld referred to the stress that can be placed on people and their families in trying to afford the care needed, submitting:

Financially, nursing homes have limited capacity to set the basic daily care fee and income and asset assessed extra fee (as this is set by the government), but individual facilities can set their deposit rates and can calculate additional fees based on the worth they set on a certain room type. Clients have to then assess what is viable, based on their financial circumstances. In our experience this is often a topic of high stress put on uneducated families or older people trying to cope independently.⁵⁴⁶

Woombye Care submitted:

There is also a large percentage in our community who struggle to access the care they need because they don't have the funds to do so. There are too many aged care providers who are in the industry to make a profit for shareholders and aren't worried about the actual care being provided and what sort of position the elderly person is in financially.⁵⁴⁷

Patricia Chardon stated 'Obscene levels of profit are currently made by some provider companies, running aged care as a business not much above the standard of alms houses of old!'⁵⁴⁸

Margaret Lawson expressed a view about the distribution of fees within the nursing home, stating:

Care providers should be limited in how much they can charge as an "administration" fee (no matter how it is presented) and funds to providers should go directly into providing support staff and support, not to supervisory or management positions (too many of these organisations are top-heavy and they forget their purpose and who it is they are supposed to be looking after).⁵⁴⁹

The Cancer Council Qld also provided the following example in relation to the high cost and the stress it places on the person and their family:

Tom (not his real name) has a life-limiting illness in the Wide Bay region. He is currently accessing respite in a private nursing facility, as he can't get into a public facility. He can access this service for the cost of his pension for three months, however if he is still alive longer than this period, the cost of a room will be in the vicinity of \$300,000 plus the general weekly fees. This has created a significant amount of stress for Tom's family, who are now having to consider what options are available, instead of focussing their time in making memories with their much-loved family member.⁵⁵⁰

⁵⁴⁵ Submission 1304, p 20.

⁵⁴⁶ Submission 1303, attachment, p 1.

⁵⁴⁷ Submission 1254, p 1.

⁵⁴⁸ Submission E543.

⁵⁴⁹ Submission E2055.

⁵⁵⁰ Submission 1303, attachment, p 2.

Some stakeholders called for more support for people in attempting to understand the costs and fees associated with RACFs.

For example, Ms Kathryn McDonnell called for the costs of having a parent in aged care made more reasonable and easier to understand. She stated 'It is a pure nightmare trying to work out all the extra daily costs. We are never told or shown how the figure is calculated and get left completely in the dark'.⁵⁵¹

Dr David McFarlane informed the committee:

*Initial negotiation with the aged care facility was more like a real estate transaction rather than a supportive entry into a care environment. There are so many fee components and possible discounts. My brothers summed this up very well: "After paying taxes for so many years and not receiving a pension, just when people are at their most vulnerable, the Government and aged care providers are out to screw you." I fully support their sentiment.*⁵⁵²

Some submitters referred to the cost of the Refundable Accommodation Deposit (RAD), advising the committee that in regional and rural areas the sale price of the person's house may not cover the cost of the deposit.

On this issue, Ms Georgina Johansen submitted:

*The marketing strategy for purchase is - sell your home and move in here. The cost of purchase is much greater than the sale price of a home in many rural areas. A personal example here is that in endeavouring to obtain a unit for an aged parent - within fifteen minutes of commencing the interview was terminated by the facility manager saying your parent cannot afford to come here.*⁵⁵³

One submitter who requested their name be withheld also raised concerns about the 'current, and ever increasing, costs for the Refundable Accommodation Deposit (RAD)', advising that in regional Queensland a prospective resident's home can fetch far less than the required RAD. This submitter advised:

*This is putting a terrible strain on families (who themselves are at retirement age) as they try to cover the RAD balance rather than the resident (or family) having to pay the exorbitant interest rate (was 5.72% pa) charged with an ever diminishing bank balance. Not to mention the ongoing monthly costs of medication...and the daily fee for services that a resident may not use or need.*⁵⁵⁴

Some submitters called for an increase in the number of publicly funded aged care places and facilities as a means of addressing this issue. Ms Erika Gerdson submitted:

*The aged care system is not meeting the needs of Queenslanders in part because the cost of getting into an aged care home is too expensive, there are not enough publicly-funded places in aged care homes, and the amount of money taken by the aged care facility for daily/weekly expenses is too high.*⁵⁵⁵

Ms Joanne O'Shanesy similarly submitted:

There needs to be a reintroduction and expansion of a suite of State funded age care facilities such as Eventide within the SE corner and Regional areas, to provide quality aged care and reduce private profiteering. People who have paid taxes all their lives (now often until they are 70 years old) need to pay for care with their pensions. The sale of family homes to fund care, means that

⁵⁵¹ Submission 2342, p 1.

⁵⁵² Submission E1634.

⁵⁵³ Submission 2057, p 1.

⁵⁵⁴ Submission 1166, p 2.

⁵⁵⁵ Submission 1642, p 2.

*only the wealthy will leave an inheritance for their children and family. If the system continues as it now does, the rich will become richer and the poor destitute. This in turn will lead to a greater call for public services, which could be avoided by timely decision making now.*⁵⁵⁶

7.3 Supply and expenditure

7.3.1 Supply

In 2017-18, there were a total of 246,536 allocated⁵⁵⁷ and 207,142 operational residential aged care places (excluding places offered in flexible care programs). The number of consumers of residential care increased from 239,379 in 2016-17 to 241,723 in 2017-18 (an increase of 1%).⁵⁵⁸ In 2018-19 the number of people who received permanent residential aged care at some time during the year was 242,612, an increase of 889 from 2017-18. On 30 June 2019, there were 182,705 people receiving permanent residential care. The average completed length of stay was 34.4 months.⁵⁵⁹

In 2017-18, the average occupancy rate across all residential care places was 90.3 per cent, down from 91.8 per cent in 2016-17 and 92.4 per cent in 2015-16. This decline over the last two years follows relative stability for several years at above 92 per cent. Occupancy is measured as the total number of days an allocated place is occupied by a resident, divided by the total number of days an allocated place was available to be occupied. Occupancy rates reflect both demand and the number of places available. The 1.5 per cent decline in the occupancy rate in 2017-18 was contributed to by the growth in the number of bed days available (3.0 per cent) which grew at twice the rate of the growth in care days provided (1.4 per cent).⁵⁶⁰

Queensland recorded the lowest occupancy rate of 89.1 per cent after being relatively high in recent years (92.8 per cent in 2013-14, 92.7 per cent in 2014-15, 92.2 per cent in 2015-16, and 92.3 per cent in 2016-17).⁵⁶¹

The ACFA has stated that in its consultation with the sector, some providers have expressed concern that falling occupancy rates will put pressure on the viability of some residential aged care facilities, noting that only a small decline in occupancy can have a significant impact on their overall financial performance. A few providers said that they have been reducing accommodation prices in an effort to attract new residents.⁵⁶²

⁵⁵⁶ Submission 1791, p 4.

⁵⁵⁷ Compared to 247,907 allocated places as at 30 June 2017, while the number of operational places increased by 6,453 as provisional allocations and offline places came online. The overall reduction in allocated places was due to no new places being allocated during 2017-18 (as there was no ACAR) and 1,371 provisionally allocated places were either surrendered by providers or revoked by the Department.

⁵⁵⁸ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 6, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵⁵⁹ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 45, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁵⁶⁰ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 39, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵⁶¹ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 40, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵⁶² Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, pp X, 40-41, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

The Australian Government has announced in-principle support to the proposal to transition the allocation of residential care places from the current ACAR approach to alternative arrangements that provide greater choice for older Australians. The Centre for Health Economics Research and Evaluation at the University of Technology Sydney, in collaboration with aged care accounting and business advisory firm StewartBrown and the Department of Health, are undertaking an impact analysis looking at potential alternative arrangements. One of the options would be to move to a model, similar to home care, where the consumer is assigned a residential care place. This would create greater competition for consumer custom, potentially putting further pressure on occupancy rates for some providers.⁵⁶³ This was originally recommended by the Tune Review.

Nationally, not-for-profit providers (comprising religious, charitable and community-based providers) were responsible for 55.3 per cent of operational residential care places, for-profit providers were responsible for 40.6 per cent, and government providers for 4.2 per cent.⁵⁶⁴ As mentioned earlier, the Queensland Government provides approximately three per cent of residential aged care places via its aged care facilities.

7.3.2 Expenditure

Australian Government expenditure on residential care in 2018-19 was \$13.0 billion, up from \$12.2 billion in 2017-18 and \$11.9 billion in 2016-17.⁵⁶⁵

Table 14: Australian Government recurrent residential care funding, 2014–15 to 2018–19, by state and territory

State/Territory	2014–15 \$M	2015–16 \$M	2016–17 \$M	2017–18 \$M	2018–19 \$M	% Change 2017–18 to 2018–19
NSW	3,563.5	3,836.3	3,992.5	4,053.9	4,270.3	5.3
Vic	2,758.6	2,976.2	3,144.8	3,247.6	3,465.5	6.7
Qld	1,926.4	2,061.9	2,189.1	2,274.2	2,465.8	8.4
WA	921.1	972.0	996.4	1,029.8	1,120.0	8.8
SA	1,018.2	1,084.3	1,116.6	1,126.9	1,194.0	6.0
Tas	258.0	278.5	290.9	295.0	312.0	5.8
ACT	110.6	126.0	134.2	137.9	144.3	4.6
NT	33.1	35.7	39.1	38.9	42.6	9.4
Australia	10,589.4	11,371.4	11,903.8	12,204.2	13,014.5	6.6

Note: Totals may not sum exactly, due to rounding. This table includes funding through the Department of Veterans' Affairs. This table presents recurrent funding to residential care providers using accrual based reporting. Due to accrual adjustments, for smaller jurisdictions in particular, this can lead to significant year-on-year variation. Based on claims data between 2017–18 and 2018–19, the growth in recurrent funding for each state and territory ranged from -4.6 per cent to 11.1 per cent.

Source: Australian Government, Department of Health, 2018-19 Report on the Operation of the Aged Care Act 1997, p 46.

⁵⁶³ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, pp 40-41, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵⁶⁴ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 12. This is the number of operational residential aged care places at a particular date (30 June 2018); Australian Government, Department of Health, 2017–18 Report on the Operation of the Aged Care Act 1997, p 2, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁵⁶⁵ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 8, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

The table above shows the Australian Government recurrent residential care funding by state and territory between 2013–14 to 2018–19.

Across Australia, in 2017–18, residents contributed over \$4.5 billion toward their living expenses, care and accommodation (excluding lump sum accommodation deposits).⁵⁶⁶ Residents contributed \$3.3 billion towards their living expenses, \$780 million towards accommodation costs by those who chose to pay through a Daily Accommodation Payment (which excludes those choosing to pay through a fully refundable lump sum deposit) and \$504 million towards care costs. Overall contributions from residents (excluding lump sum deposits) represent 26.6 per cent of total residential care provider revenue.⁵⁶⁷

7.3.3 Issues with supply and expenditure

Stakeholders identified the waiting time for a place in a suitable aged care facility as an issue during the Inquiry, particularly for those in rural and remote areas, those on low incomes or without the financial resources to purchase a place, and older Queenslanders with dementia or mental health issues.

7.3.3.1 Wait lists for residential aged care facilities

The length of time that an older person has to wait for a place in a suitable aged care facility was raised as an issue by a number of stakeholders.⁵⁶⁸

QNMU told the committee:

*The waiting times for placement in a residential aged care facility can be unacceptably long... The requirement of placement in a residential aged care facility is often urgent and stressful for individuals and their significant others... The decision to enter a residential aged care facility is not an easy one and is often made with some sense of urgency as an older person progresses to a level of care that cannot be provided in the community setting. As identified by the Productivity Commission (2019), the median elapsed time from Aged Care Assessment Team (ACAT) approval to entering a residential facility was 121 days in 2017-18, up from 84 days in 2015-16 with only 44.7% of older people entering care within three months.*⁵⁶⁹

COTA Queensland advised the committee that in Queensland in 2013, the median wait time for entry to residential aged care was close to 50 days. By 2016–17, the wait time had extended to 135 days, with the trend to longer wait times continuing: in 2017–18, the median wait time had increased to 141 days.⁵⁷⁰

CentaCareCQ provided an example of the financial cost of the wait for a place in a residential aged care facility:

In Mackay, there is an example of a person with a home care package, waiting for a place in a residential facility, being admitted to hospital in Mackay in early September 2018, and at the time of writing this response still being in hospital. However, the client was offered a transfer to the Bowen Hospital as Mackay hospital didn't have space. This transfer was declined as Bowen is 190km from Mackay. In addition, after 28 days in hospital a co-payment is triggered (\$60 per

⁵⁶⁶ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 8, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵⁶⁷ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 22, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵⁶⁸ See, for example, submissions 1201, 1207, 1213, 1297, 1304, 1642.

⁵⁶⁹ Submission 1213, p 13.

⁵⁷⁰ Submission 1304, p 19.

*day). For this particular client, the inadequacy of the waiting times has also resulted in increased financial stress.*⁵⁷¹

The QLS noted that while metropolitan areas do not appear to have significant waiting periods for entry into an aged care facility, there may be significant waiting periods for a resident to gain entry into their preferred aged care facility.⁵⁷²

Some stakeholders advised that due to a lack of equity of access, some older people will wait longer than others for a place in an RACF. For example, Queensland PHNs referred to the cherry-picking of residents by RACFs in certain geographic locations or with a strong reputation, impacting on equitable access:

Cherry-picking leads to lack of equity of access within residential aged care. Data releases on waiting times for both residential and home care places show that needs are increasingly not being met as budget and package releases are not keeping up with demand. In residential aged care the data is only part of the story. While there are increasing numbers of vacancies in residential aged care, there are often long waiting lists at certain facilities, i.e. those in particular geographical locations, or where the facility has a strong reputation or is regarded as a high quality service.

*As a result, these facilities are able to cherry pick older people with less complex needs and Queensland Health owned facilities are left to pick up the most complex patients, e.g. bariatric patients entering residential aged care who require costly equipment and present with challenges accommodating the needs of these older people within the residential aged care pricing structure.*⁵⁷³

In its submission the RANZCP advised of concerns that many older people are placed in acute hospital beds for prolonged periods of time because there are no suitable or secure placements available in RACFs, leading to a risk of bed blocking in hospitals. Of particular concern:

*...people with dementia with extreme behavioural and psychological symptoms of dementia (BPSD) (e.g. physical violence) and people with dementia with very severe BPSD (e.g. severe depression, suicidal tendencies, physical aggression) often remain in inappropriate settings for years, such as general adult inpatient units and mental health inpatient units.*⁵⁷⁴

Woombye Care also raised the issue of there not being enough beds for those who have challenging illnesses, such as a mental health diagnosis that can lead to challenging behaviours. Woombye Care advised that there are also not enough beds for those older people who don't have the money to pay the RAD's set by facilities.⁵⁷⁵

Georgina Johansen supported this view about low incomes, advising there are longer waiting times for those on low incomes who do not have the resources to purchase a unit/room, compared to those who can purchase a unit outright.⁵⁷⁶

⁵⁷¹ Submission 1297, p 3.

⁵⁷² Submission 1201, p 4.

⁵⁷³ Submission 1301, p 5.

⁵⁷⁴ Submission 1207, attachment, p 4.

⁵⁷⁵ Submission 1254, p 1.

⁵⁷⁶ Submission 2057, p 1.

Christine Boyd referred to her personal experience, stating:

*The greatest barriers we had for months, was a lack of finances, we couldn't sell the family home to raise the money for a bond, and the scarcity of availability in quality, clean, caring full time care.*⁵⁷⁷

7.3.3.2 Access and availability in regional/rural/remote areas.

Many submitters referred to the difficulties faced by older people living in regional, rural and remote areas in accessing a place in their preferred location due to a shortfall in places and a lack of available options.⁵⁷⁸

In terms of availability, LASA told the committee:

*In general sufficient residential care places are available but supply and demand varies according to geographical regions. The more rural and remote residential care providers may not have enough beds, while there may be an over-supply in metropolitan regions. Unacceptable wait times for home care packages can have the impact of more clients going into residential care, which means that some providers now have a wait-list for residential care beds.*⁵⁷⁹

Similarly, SVHA stated that while industry data indicates industry occupancy rates for aged care are declining, suggesting there is bed capacity in the current system, it is SVHA's experience that the ability of residents to access the right care, with the right carers, in their location is still a challenge. SVHA submitted:

*...with such a decentralised population, the distribution of facilities and an appropriately skilled workforce is a strategic challenge for Queensland. So, while on paper and/or in data there are indications the "numbers are right" to address demand, the distribution of service providers and beds, and the presence of a local well-trained and experienced aged care workforce, needs to be factored into the planning of the state's aged care system.*⁵⁸⁰

The Cancer Council Qld noted that while some regional centres have seen several new facilities built in recent years, the demand still appears to be much higher than supply.⁵⁸¹

Stakeholders also spoke of the need for older people to move away from their local community, family and friends to be able to access care in an RACF. For example, the QLS advised that regional areas report delays in placements into aged care can eventuate in a placement many kilometres from the adult's last address.⁵⁸²

The Queensland Policy Advisory Group from National Seniors Australia noted they had been told by seniors that they struggle to find a suitable service that is located near family, especially people in rural and remote areas, where some are having to travel significant distances to access residential care, far away from family and community.⁵⁸³

Margaret Lawson told of older people having to move out of their local area to access a place in an RACF:

If they enter residential aged care, then they should be located in their town near their family or friends. Where I live, I know several cases where aged persons were sent to live in residential

⁵⁷⁷ Submission E855.

⁵⁷⁸ See, for example, submissions E738, 1207, 1280, 1283, 1301, 2057.

⁵⁷⁹ Submission 1283, attachment, pp 2-3.

⁵⁸⁰ Submission 1280, pp 11-12.

⁵⁸¹ Submission 1303, attachment, p 1.

⁵⁸² Submission 1201, p 4.

⁵⁸³ Submission 1309, p 3.

*aged care two to three hours drive away and, when their family ask for them to be moved back, they are told the beds are for local people. Excuse me! They ARE local and have been arbitrarily moved. I know of several people this has happened to, and it is a day trip for family members to visit them. Other family members or their friends can only visit if another family member drives them because they are too old to drive for four to six hours on country roads, or they no longer have a licence. The cost of travel is also a big factor.*⁵⁸⁴

Ms Anita Groos submitted that services need to be located close to where people live, accepting that this is difficult in rural and remote areas. She suggested that it may be preferable to locate more aged care in regional centres (rather than use remote hospital beds), and that provisions should be made to allow family members to travel to the aged care facility to visit their loved one regularly.⁵⁸⁵

The QNMU referred to data produced by the Australian Institute of Health and Welfare (2019), which showed that the average occupancy rate across the sector was 90% with three out of five facilities (62%) located in urban areas. Based on these statistics, the QNMU stated:

These statistics highlight the problems of service delivery in regional, rural and remote areas common to health, aged care and social services. These include:

- *the tyranny of distance;*
- *workforce and skill shortages and recruitment and retention difficulties;*
- *poor wages and conditions which act as a disincentive;*
- *lack of service providers and services;*
- *lack of supporting infrastructure, e.g. health services;*
- *increased costs of service provision.*⁵⁸⁶

COTA QLD referred to the Royal Flying Doctor Service's statement:

*...that poor provision of aged care in the bush leads to older patients being relocated to areas of higher provision. They report that people in remote locations feel they have no option about leaving their communities for aged care, becoming '... socially disconnected from all they knew and loved and forced into exile'. The study found that feelings of aloneness were common, with many participants believing their loved ones died more quickly due to being relocated from their rural and remote communities.*⁵⁸⁷

In contrast, Churches of Christ submitted that there are beds available in most communities throughout the state (including regional, rural and remote areas) to support citizens seeking residential aged care, with occupancy rates averaging less than 93% in general. They also stated that most communities have planned respite (usually for minimum 1 or 2 weeks) available, although there may be a shortage of emergency short-term respite. Churches of Christ suggested the availability of emergency short-term respite may be impacted by the high administrative and regulatory requirements for residential aged care admissions.⁵⁸⁸ Churches of Christ expanded on this, submitting:

With 28 services throughout metropolitan, regional, rural and remote locations, we are generally able to accommodate resident's required residential aged care. Exceptions to this are in some cases where people are seeking a secure dementia unit for their family member – these are generally in high demand. As well, where there is availability, it may not be the service of choice,

⁵⁸⁴ Submission 2055.

⁵⁸⁵ Submission E688.

⁵⁸⁶ Submission 1213, pp 15-16.

⁵⁸⁷ Submission 1304, p 12.

⁵⁸⁸ Submission 1281, p 3.

or it may be in a shared rooms or a room with shared bathroom, etc. There have been until recently a shortage of RAC beds in Toowoomba. However the opening of 2 new services in the first half of 2019 is expected to address this unmet demand. In some instances, people are assessed as being eligible for RAC but whose needs are what would be termed 'low care'. Where services are staffed to meet high care needs (i.e. generally where a person requires access to 24/7 registered nursing care), it is generally not viable to offer beds to people with low needs as government subsidies associated with low care needs are not sufficient to cover staffing costs at most RAC services. The availability of Home Care packages throughout Queensland is insufficient to meet current and future needs, forcing many into RACFs services earlier than they would have preferred in order to access care and services.⁵⁸⁹

The Royal Commission's interim report discussed issues regarding access and availability of aged care in regional and remote communities, and outlined concerns with the centralisation of the aged care system.

The Royal Commission has heard a range of opinions about the impact of this centralisation, including:

- *although providers, consumer advocates and other interested parties were consulted on the changes, the end result is still very much a bureaucratic, Canberra-based, centralised product with a distinct lack of flexibility, responsiveness and individual and regional focus*
- *there is a lack of options in rural and particularly remote areas; and some 'absentee providers' operating without a local office or a real understanding of the local population*
- *there is an absence of alternative approaches with guaranteed funding, for remote service provision or for services delivered into Aboriginal and Torres Strait Islander communities.⁵⁹⁰*

...

In submissions to the Royal Commission, several people have pointed out that this centralised approach obscures local information and means that providers do not have enough information to enable them to develop comprehensive models of service provision in particular areas. As well as creating problems for providers, centralisation has left many individuals without support to access the entry pathway to aged care or to coordinate and manage services once they start receiving them.⁵⁹¹

7.4 Residential Respite Care

Residential respite care provides short-term planned or emergency residential aged care in Australian Government subsidised aged care services and is provided in a number of settings to allow flexibility for users.⁵⁹² To access residential respite a person must be assessed as eligible by an ACAT. An ACAT

⁵⁸⁹ Submission 1281, p 5.

⁵⁹⁰ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 139, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁵⁹¹ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 139, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁵⁹² Queensland Health, correspondence dated 23 January 2019, p 5; Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 13; Australian Government, Department of Health, 2017–18 Report on the Operation of the Aged Care Act 1997, p 2, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

will determine whether a person is eligible for high-care or low-care residential respite.⁵⁹³ The distinction between high and low care was not removed from respite care when it was removed from permanent residential care on 1 July 2014.⁵⁹⁴ The determination of care levels does not affect the type of care provided, but can impact the applicable fees and Government subsidies.⁵⁹⁵

Once approved by an ACAT, a person can receive residential respite in aged care facilities for up to 63 days each financial year (this can be extended when an ACAT considers it necessary). People receiving residential respite are entitled to receive the same services as someone receiving permanent residential aged care, including assistance with meals, laundry, room cleaning, personal grooming, and nursing care.⁵⁹⁶

There is not a separate allocation of respite places for providers of residential care. Rather, a portion of each permanent allocation of residential care places is used for the provision of respite care. It is a matter for the provider as to what mix of respite and permanent residential care places to deliver within the financial year. Currently they have to contact the Department of Health to seek approval.⁵⁹⁷

In 2018–19, there were 2,579 residential aged care homes which provided residential respite services nationally, while in Queensland there were 443 residential respite service providers 2018–19.⁵⁹⁸

According to ACFA, the number of people accessing residential respite care is increasing proportionally faster than those accessing permanent residential care. Throughout 2018–19, a total of 65,523 people received residential respite care, which is an increase on 2017–18 with 61,993 receiving care, and 2016–17 with 59,228 receiving residential respite care.⁵⁹⁹ Although there were no changes made to the

⁵⁹³ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 29, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁵⁹⁴ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 45, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵⁹⁵ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 29, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁵⁹⁶ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 13.

⁵⁹⁷ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 29, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf; Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 45, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁵⁹⁸ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 29, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁵⁹⁹ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 39, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf; Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 29; Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 38, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

operation of residential respite care, since 1 July 2014 the rate of increase in consumers of respite care is more than triple that of the increase of permanent residents.⁶⁰⁰

A trend that has been emerging since 2014-15 and continued in 2017-18 is that the number of respite consumers accessing high level respite care is increasing while the number accessing low level respite care is decreasing. The ACFA suggests that the significant difference in funding for providers between high and low care is potentially serving as a disincentive to providers taking respite consumers who had only been approved for low level care.⁶⁰¹

The number of residential respite days used in 2018-19 was 2.2 million, an increase of nearly 130,000 days since 2017-18. On average, each recipient received 1.3 episodes of residential respite care during 2018-19, and their average length of stay per episode was 25.8 days.⁶⁰²

A significant difference in respite care compared with permanent residential care is that respite residents do not make any means-tested accommodation or care contributions. They can however be asked to pay the basic daily fee for living expenses, which is at the same rate as permanent residents. Respite residents can also purchase additional services, in the same manner as a permanent resident.⁶⁰³

The Australian Government sets the maximum level of the basic daily fee that providers may ask residential respite care recipients to pay (standard resident contribution), which equates to 85 per cent of the single rate of the basic age pension. However, it is at the provider's discretion whether they charge the residential respite care recipient the maximum level of the basic daily fee. This fee is used by the approved provider to cover costs such as cleaning, maintenance and laundry.⁶⁰⁴

The Australian Government pays the provider a residential respite subsidy and a respite supplement for each eligible respite resident. The subsidy and supplement are paid at either a low or high rate depending on the level of respite care the consumer is approved for by the ACAT. Additionally, facilities that use 70 per cent or more of their respite allocation over a 12 month period receive a higher daily respite supplement rate per eligible high care recipient. Respite subsidies are indexed on 1 July each year. Respite supplements are indexed on 20 March and 20 September each year in line with pension indexation.⁶⁰⁵

⁶⁰⁰ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 45, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁶⁰¹ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 49, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁶⁰² Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 39, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁶⁰³ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 45, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁶⁰⁴ Australian Government, Department of Health, 2017-18 Report on the Operation of the *Aged Care Act 1997*, p 30, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁶⁰⁵ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 96, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

7.5 Pricing and prudential oversight

The Aged Care Act provides that the Minister may determine the maximum amount of accommodation payment that a residential aged care provider may charge a person, and that aged care providers must apply to the Aged Care Pricing Commissioner for the Commissioner's approval to charge accommodation payments that are above this maximum amount.⁶⁰⁶

The functions of the Aged Care Pricing Commissioner include:

- the approval of extra service fees
- the approval of proposed accommodation payments that are higher than the maximum amount determined by the Minister, and
- any other functions conferred on the Aged Care Pricing Commissioner by the Minister or under Commonwealth law.⁶⁰⁷

The current maximum amount that a provider may charge a care recipient without approval from the Aged Care Pricing Commissioner is \$550,000 as a Refundable Accommodation Deposit or its equivalent.⁶⁰⁸

There are strict prudential requirements related to the accounting and handling of bonds and refundable accommodation deposits (RADs) collected by approved providers. The department closely monitors how effectively providers are meeting these requirements and conducts an annual review of providers' prudential arrangements.⁶⁰⁹

Refundable accommodation deposits (which include accommodation bonds and/or entry contributions) must comply with the prudential requirements stated in the Aged Care Act and set out in the *Fees and Payments Principles 2014 (No.2)*. The prudential requirements aim to protect RADs paid to providers by recipients of aged care services.⁶¹⁰

The four Prudential Standards (Liquidity, Records, Disclosure, and Governance) seek to reduce the risk of providers defaulting on their RAD balance refund obligations to care recipients, by requiring providers to:

- systematically assess their future obligations with RADs and the associated funding implications to ensure that they are able to meet their refund obligations as they fall due
- establish and maintain a register that records information about RADs and the care recipients who pay them

⁶⁰⁶ Australian Government, Aged Care Pricing Commissioner, New Applications for Accommodation Payments, <http://www.acpc.gov.au/internet/acpc/publishing.nsf/Content/approval-of-accommodation-payments>

⁶⁰⁷ Australian Government, Aged Care Pricing Commissioner, The Aged Care Pricing Commissioner, <http://www.acpc.gov.au/internet/acpc/publishing.nsf/Content/about>.

⁶⁰⁸ Australian Government, Aged Care Pricing Commissioner, New Applications for Accommodation Payments, <http://www.acpc.gov.au/internet/acpc/publishing.nsf/Content/approval-of-accommodation-payments>.

⁶⁰⁹ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 17, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁶¹⁰ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 50. https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

- establish and document governance arrangements for the management and expenditure of RADs (only to be used for permitted uses)
- promote transparency of their financial management by disclosing information to care recipients, prospective care recipients and the department about their financial information and prudential compliance, and how they manage the RADs.⁶¹¹

The Accommodation Payment Guarantee Scheme (Guarantee Scheme) was established under the *Aged Care (Accommodation Payment Security) Act 2006*. If a provider becomes insolvent and defaults on its obligation to refund a RAD, the Guarantee Scheme enables the Government to pay care recipients an amount equal to each RAD balance. The Guarantee Scheme is triggered if the provider has been placed into bankruptcy or liquidation and there is at least one outstanding RAD.⁶¹²

Through the Accommodation Payment Guarantee Scheme, the Australian Government protects residents' accommodation bonds and/or entry contributions if a residential aged care provider becomes insolvent and is unable to meet its obligation to refund a lump sum accommodation payment.

7.6 Care provided in aged care facilities

The care provided in RACFs is guided by the following:

- Charter of Aged Care Rights (see section 10.1)
- Aged Care Quality Standards (see section 11.1.1)
- Mandatory Quality Indicator Program (see section 10.2)
- Serious Incident Response Scheme (SIRS) (see section 10.3).⁶¹³

Further information is provided in the relevant sections of the report as noted above.

Residential aged care providers also have specific responsibilities that relate to the use of physical and chemical restraints. These responsibilities are set out in the Quality of Care Principles, which are made under the Aged Care Act.

In a study on the interface between the aged care and health systems in Australia undertaken by the Australian Institute of Health and Welfare, it was found that people in RACFs were more likely to have had at least one antipsychotic prescription dispensed (28%) compared with those receiving home support (4%) or home care (8%) services.⁶¹⁴

Concerns about the overuse of physical and chemical restraints on residents in residential care were also raised during the committee's investigation into the sudden closure of the Earle Haven facility.

The QNMU expressed the view that issues regarding restraint in aged care have been well documented in the Royal Commission hearings to date. Regarding physical restraint, the union stated its view:

⁶¹¹ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 50, https://www.gen-agedcaredata.gov.au/www_aihwwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁶¹² Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 50, https://www.gen-agedcaredata.gov.au/www_aihwwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁶¹³ <https://www.health.gov.au/health-topics/aged-care/providing-aged-care-services/delivering-quality-aged-care-services>.

⁶¹⁴ Australian Institute of Health and Welfare, *Interfaces between aged care and health systems in Australia – first results*, November 2019, p 9, <https://www.aihw.gov.au/reports/aged-care/interfaces-between-the-aged-care-and-health-system/contents/summary>.

*... that physical restraint should be used only as a last resort when there is an imminent risk of serious harm to the resident or others after all other strategies have been tried and failed.*⁶¹⁵

With regard to chemical restraint, the union stated:

... [M]edication should be prescribed for residents only when there is a clinical need. Whilst the behavioural and psychological symptoms of dementia can create disruption and risk within an aged care facility, the use of medication should never be a substitute for appropriate surveillance by a sufficient number of registered and enrolled nurses.

*It is our view that the prevalence of the use of restraint in aged care, whether physical or chemical, is a symptom of the chronic understaffing of residential aged care services, as illustrated above. Appropriate staffing and skill mix, along with training in minimising the impact of the behavioural and psychological symptoms of dementia, would go a long way to reducing restraint in aged care.*⁶¹⁶

In commenting on regulation of these practices, the union observed:

The federal government lacks effective policy and practice guidelines for the use of restraint in aged care. Queensland however has quite prescriptive policies and practice guidelines regarding restraint, relevant to mental health services, published by the Chief Psychiatrist. They focus on the safety and dignity of the patient, including reduction and elimination plans and, significantly, mandate the immediate reporting of the use of restraint.

*We note here that physical restraint in aged care is the equivalent of mechanical restraint described by the Chief Psychiatrist. The federal government would do well to adapt these policies and guidelines for use in aged care.*⁶¹⁷

Again on the question of regulation in this sphere Mr Greg Rowe, Chief Executive Officer of ADA Australia, submitted:

The Commonwealth government, just prior to the recent election, brought in new principles associated with the administration of chemical and physical restraint in aged care. I appeared before the Joint Parliamentary Committee on Human Rights about three weeks ago, arguing that those new principles should be repealed. They breach people's human rights. They make it easier to administer that medication than currently. You are just required to have a responsible person. A responsible person could be the gardener who signs off and gives permission.

*If we go back to the disability legislation in Queensland around the use of restrictive practices, our legislation is world leading. We have invested in protecting Queenslanders with a disability but we have ignored Queenslanders who are ageing, and I do not understand that. Having come out of the disability sector, as I said, human rights is front row and central to the legislation. It is underpinned by a rights statement. In aged care you cannot find a rights statement. People have no rights. Well, that is how it would appear.*⁶¹⁸

The committee, in its report from that investigation, noted that complaints of the excessive use of restraint as practised at Earle Haven are of great concern.

The Australian Government strengthened its controls on restraint on residents in aged care in the Quality of Care Principles under the Aged Care Act in November 2019. The Quality of Care Amendment (Reviewing Restraints Principles) Principles 2019 came into effect on 29 November 2019 and now:

- make it clear restraint must always be used as a last resort

⁶¹⁵ Submission EH003, p 9.

⁶¹⁶ Submission EH003, p 10.

⁶¹⁷ Submission EH003, p 10.

⁶¹⁸ Public hearing transcript, Gold Coast, 12 September 2019, p 12.

- refer to state and territory legislation for prescribers' responsibilities regarding informed consent
- require a 12-month review of the restraint regulation operations to ensure they are minimising the use of inappropriate restraint.⁶¹⁹

7.7 Staffing of residential aged care facilities

Under the Aged Care Act providers are obliged to maintain an adequate number of appropriately skilled staff to ensure that the care needs of care recipients are met.⁶²⁰ The Aged Care Act makes no further direction on the number of staff or the skill mix of the staff required to meet the care needs of residents.

The Department of Health stated in its report, *Future of Australia's Aged Care Sector Workforce*:

*The nature and extent of aged care work can vary, depending on the needs of care recipients, the care service's size and design, the way work is organised and the extent to which some services are delivered in-house or outsourced. Requirements will also change over time within individual residential care homes, as changes occur in the needs and acuity of care recipients.*⁶²¹

In terms of staffing, LASA advised the committee:

*Aged care services operate with differing levels of staffing, depending on their mix of residents and for this reason they use different models to determine the sufficiency of staff...Aged care services operate under various models to determine appropriate staff mixes. Surveys of consumer and resident care needs are undertaken regularly by home care and residential care providers to determine the appropriate mix of staff. The appropriateness of aged care providers' staffing levels and mix are monitored by the regulatory authorities.*⁶²²

The workforce providing direct care services in Australia traditionally comprised three distinct occupational groups; namely, Registered Nurses (RN), Enrolled Nurses (EN), and Personal Care Workers (PCW). In response to the increasing demands of aged care services, coupled with a limited aged care workforce, the scope has been extended to include Allied Health Assistants and Nurse Practitioners (NP). The AHA and NP roles are recent developments within the aged care workforce. The nurse practitioner model was an initiative introduced by the Australian government with the aim of improving access to primary health care delivery.⁶²³

Residential aged care facilities tend to rely increasingly on PCWs. PCWs are the largest occupational group in residential aged care, comprising around 70 per cent of the workforce.⁶²⁴

⁶¹⁹ Australian Government, Department of Health, *Minimising Restraints in Aged Care*, <https://www.health.gov.au/health-topics/aged-care/providing-aged-care-services/working-in-aged-care/minimising-restraints-in-aged-care>.

⁶²⁰ *Aged Care Act 1997* (Cth), section 54.1(1)(c).

⁶²¹ Australian Government, Department of Health, *Future of Australia's Aged Care Sector Workforce*, pp 117-118, <https://www.health.gov.au/resources/publications/future-of-australias-aged-care-sector-workforce>.

⁶²² Submission 1283, p 3.

⁶²³ Bankwest Curtin Economics Centre, *Developing Sustainable Pathways for Aged Care Workers: A WA Case Study*, BCEC Research Report No. 13/18, April 2018, p 10, <https://bcec.edu.au/assets/BCEC-Report-Developing-sustainable-career-pathways-for-aged-care-workers.pdf>.

⁶²⁴ Australian Government, Department of Health, *The Aged Care Workforce*, 2016, March 2017, p 12, https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/03_2017/nacwcs_final_report_290317.pdf.

Volunteer workers also make a significant contribution across the sector.⁶²⁵ In 2016, it was estimated that there were over 366,000 paid workers in aged care with a further 68,000 volunteers.⁶²⁶

7.7.1 Minimum standards of staffing for State-operated aged care services

On 4 September 2019, Hon Dr Steven Miles MP, Minister for Health and Minister for Ambulance Services, introduced the Health Transparency Bill 2019. The parliament passed the Bill on 28 November 2019 and it received assent on 5 December 2019.

The *Health Transparency Act 2019* has three policy objectives:

- minimum standards of staffing and care for public residential aged care facilities
- health transparency in public and private facilities, and
- reforms to the *Health Ombudsman Act 2013*.

The first two of these objectives are relevant to this report and will be discussed in the following sections.

7.7.1.1 *Minimum standards of staffing and care for public RACFs*

The *Health Transparency Act 2019* amended the *Hospital and Health Boards Act 2011* to prescribe by regulation an average daily resident care hour requirement and a minimum nurse and support worker skill mix ratio for the 16 state owned RACFs.⁶²⁷ To date this part of the *Health Transparency Act 2019* has not commenced.⁶²⁸ Therefore the corresponding regulation has not been made. However, The Minister for Health and Minister for Ambulance Services tabled the Draft Hospital and Health Boards (State Aged Care Facilities) Amendment Regulation 2019 alongside the Bill, which prescribed intended minimum nurse workforce for public RACFs:

- a minimum nurse percentage, that is, registered nurses and enrolled nurses of 50 per cent of the workforce, with a minimum of 30 per cent required to be registered nurses during a 24 hour period, and
- a minimum average daily resident care requirement of 3.65 hours.⁶²⁹

7.7.1.2 *Health transparency in public and private facilities*

The *Health Transparency Act 2019* establishes a legislative framework to compel public and private health facilities and RACFs to provide certain information, and to enable that information to be published.⁶³⁰ It is intended that information collected will be reported on a new website.⁶³¹

The Act sets out the type of information to be collected including:

- general information such as address and contact details
- quality and safety information, and

⁶²⁵ Australian Government, Department of Health, A Matter of Care: Australia's Aged Care Workforce Strategy, p 5, <https://www.health.gov.au/sites/default/files/a-matter-of-care-australia-s-aged-care-workforce-strategy.pdf>.

⁶²⁶ National Institute of Labour Studies, *2016 National aged care workforce census and survey – the aged care workforce*, 2017, pp 158-9, <https://www.gen-agedcaredata.gov.au/Resources/Reports-and-publications/2017/March/The-aged-care-workforce,-2016>.

⁶²⁷ *Health Transparency Act 2019*, s 69, insertion of new S138H and 138I Hospital and Health Boards Act 201.

⁶²⁸ These provisions will commence on proclamation. *Health Transparency Act 2019*, s 2.

⁶²⁹ Draft Hospital and Health Boards (State Aged Care Facilities) Amendment Regulation 2019.

⁶³⁰ Health Transparency Bill 2019, Explanatory notes, p 9.

⁶³¹ Health Transparency Bill 2019, Explanatory notes, p 9.

- residential care information.⁶³²

Definitions and examples of these types of information are set out in sections 8-10 of the *Health Transparency Act 2019*. The explanatory notes state that specific types of quality and safety information and residential care information, to be sought from health facilities and RACFs will be set out in subordinate legislation.⁶³³ The Minister tabled draft subordinate legislation titled Draft Health Transparency Regulation 2019 alongside the Bill so that the proposed legislative framework could be considered holistically.⁶³⁴

The draft Health Transparency Regulation 2019 set out the following information requirements:

- for each private health facility, the number of cases of staphylococcus aureus bacteraemia at the facility in a particular period is prescribed
- the average daily resident care hours at each state aged care facility or private residential aged care facility for a particular period.⁶³⁵

At the time of writing, subordinate legislation for the *Health Transparency Act 2019* has not been made.

7.7.1.3 Health transparency in private RACFs

The *Health Transparency Act 2019* enables the chief executive, to collect and publish general information and residential care information that relates to private RACFs.⁶³⁶ However, the *Health Transparency Act 2019* does not compel the RACF to provide the information requested. It does however, compel the RACF to respond in 15 days with some of that information, all of that information or a notice that none of the information will be provided.⁶³⁷

The chief executive may publish the information or the response provided.⁶³⁸

7.7.1.4 Health transparency in public RACFs.

In the case of state owned RACFs, the chief executive may collect and publish general information and residential care information.⁶³⁹ However, unlike their private facility counterparts, public RACFs, are compelled to provide the information requested.⁶⁴⁰ Moreover, there is no option to submit a response that some or none of the information will be provided.⁶⁴¹

7.7.1.5 How the information will be published

It is intended that information will be published on a new interactive website.⁶⁴² At a public hearing in Brisbane, Dr Wakefield, Director-General of Queensland Health explained:

A new Queensland Health website will be developed to improve the transparency of the health and aged-care sectors in Queensland. The website, co-designed with consumers, will be an easy way to access information about health and residential aged-care facilities that is up to date,

⁶³² *Health Transparency Act 2019*, ss 8-10.

⁶³³ Explanatory notes, Draft Health Transparency Regulation 2019, p 2.

⁶³⁴ Queensland Parliament, Record of Proceedings, 4 September 2019, p 2641.

⁶³⁵ Draft Health Transparency Regulation 2019, p 2.

⁶³⁶ *Health Transparency Act 2019*, s 13.

⁶³⁷ *Health Transparency Act 2019*, s 15.

⁶³⁸ *Health Transparency Act 2019*, ss 11, 16.

⁶³⁹ *Health Transparency Act 2019*, s 17.

⁶⁴⁰ *Health Transparency Act 2019*, s 20.

⁶⁴¹ *Health Transparency Act 2019*, s 20.

⁶⁴² Health Transparency Bill 2019, Explanatory notes, p 9.

*informative and Queensland focussed. The website will provide a single point of reference for consumers to view and compare information about public and private hospitals, health facilities and residential aged-care facilities.*⁶⁴³

7.8 Issues with Residential Aged Care Services

Stakeholders raised a range of issues regarding the delivery of aged care in RACFs, including inadequate staffing, poor quality of care, dangerous practices in relation to restraint and medication provision and a lack of appropriate support for the most frail and vulnerable, especially those needing palliative care. These issues are summarised in the sections below. The issue of inequitable access to health care has already been discussed in section 4.3.

7.8.1 Staffing

Many submitters raised issues in relation to the staffing of RACFs, claiming they are understaffed which impacts on the time and care provided to residents, with the staff available often being inexperienced and/or not properly trained. There were numerous calls for minimum staffing ratios and an increase in the number of registered nurses available at RACFs, particularly at night time and on weekends.

7.8.1.1 Staff to patient ratios

Submitters and witnesses referred to there being insufficient staff to see to all the needs of RACF residents, resulting in not enough time being allocated to caring duties and inadequate care being provided to residents.⁶⁴⁴

The QNMU told the committee that in their audit of over 80 private sector aged care facilities in Queensland in May 2018, it was found that residents received an average of 2.61 hours of care per day compared to the research based requirement of 4.3 hours of care per day.⁶⁴⁵

Aged Care in Crisis assessed whether there are sufficient staff to provide acceptable care and concluded that when current levels of staffing are compared with international standards, there are not enough staff or sufficient skills in the sector to provide adequate care. They submitted:

The figures show that US residents get double the amount of care from both registered nurses and Enrolled nurses and overall one third more nursing care (1 hour) each day than Australian residents.

In the USA extensive data is collected and made available to prospective residents. A website in the USA has worked with a leading authority who has been involved in collecting and evaluating staffing data and analyzing it since the early 1990s. They have put words to figures by classifying them into 5 groups. Well over half of Australian nursing homes would fall into the poorest group classified as 'dangerously low'.⁶⁴⁶

National Seniors Australia also told the committee that a common element within feedback they have received was a view that substandard care is, more often than not, a product of staff not having adequate time to attend to the needs of individuals in care. This was especially acute for those who were most frail or with dementia.⁶⁴⁷

Ms Anna Doneley referred to the implications of Queensland's *Human Rights Act 2019* for staffing, submitting the *Human Rights Act 2019*:

⁶⁴³ Pubic briefing transcript, Brisbane, 16 September 2019, p 1.

⁶⁴⁴ See, for example, submissions E226, 232, 362, 1263, 1301, 1540, 1680, 1989, 2055.

⁶⁴⁵ Submission 1213, p 11.

⁶⁴⁶ Submission 1227, p 6.

⁶⁴⁷ Submission 1309, p 2.

*is committed to respecting the inherent dignity and worth of all human beings and supporting the flourishing of individuals and society. If this is our law, then aged care, end-of-life and palliative care need significantly more resources. Staffing levels in nursing home[s] is [sic] inadequate and the training and vetting of personal care employees need an urgent overhaul. Parking nursing home residents in front of a television set is not care[.] Having insufficient staff and equipment to take residents to the toilet when they call for assistance is not care.*⁶⁴⁸

Ms Raylene Dore, a volunteer in a government run nursing home, told the committee:

*...it has become obvious to me that there is insufficient staff for the current workload. Residents complain about the time it takes to receive attention, particularly toileting. They are left with the indignity of using diapers which have been put on them. This is just one example of the staffing issue.*⁶⁴⁹

Ms Rhonda Nilsson also gave an example of residents in high care being prematurely classified as incontinent:

*...as it means less work for staff if they are in a nappy. I witnessed many times on my visits, that mum would have to wait more than 20 minutes for staff to assist her to go to the toilet. Mum also had Parkinsons which can make urination even more urgent. So then when she couldn't make it, what do you know, when I'm back home (I lived in Bowen), I get a reassessment that she is incontinent – no she wasn't, the staff just couldn't get to her in time.*⁶⁵⁰

Dr Carol Portman referred to facilities being too 'grossly understaffed' to provide adequate care for the numbers of people and types of medical and care issues they must deal with. She submitted:

*They are unable to monitor things like weight loss and diet. They are unable to provide enough interactive activities to meet all of the individual interests and needs of their clients. Unless family are monitoring and highlighting issues and actively involved, many of these people's needs are ignored due to the work pressure.*⁶⁵¹

Ms Caroline Humphreys, who has worked in a not-for-profit aged care facility over the past nine years, referred to the impact of understaffing on not only the personal care, but also the social and emotional support for the residents. She advised:

...one constant cry has been that the staff is overwhelmed at times by the workload and the funding available to decrease the onus of client staff ratios. This does not revolve solely around the personal care, but the social and emotional support that goes with caring for the aged.

Staff simply does [sic] not have TIME to spend being anything other than task orientated and with the shift to consumer directed care in July 2019 this void will become greater unless there is a dramatic shift in the supply of staff to provide additional time to drive this care.

*There will be a larger focus on personal choice and self- governance, which we all know requires a more personalized approach that is not time driven. With the ageing of the baby-boomers this need will only add to the already increasing numbers of aged care recipients. Therefore funding to increase client/staff ratios needs to be a priority consideration.*⁶⁵²

Particular mention was made of the care provided at night times and on weekends. For example, a submitter whose name was withheld wrote:

⁶⁴⁸ Submission E1982.

⁶⁴⁹ Submission 1899, p 1.

⁶⁵⁰ Submission 1083, p 3.

⁶⁵¹ Submission 1836, p 2.

⁶⁵² Submission 2129, p 3.

*There definitely needs to be many more staff in proportion to clients living in aged care residential homes. Far too much is expected of staff to adequately and safely care for residents, especially those with high care needs, and especially at night time and weekends.*⁶⁵³

Ms Gillian Nicholl similarly submitted:

*No one had the time to support them properly, usually only one RN for the whole establishment and the care staff were inadequately trained and had for too much to do, so only the basics got done...staff patient ratios did not exist. Night shift was worse.*⁶⁵⁴

The RANZCP also referred to poor availability of out-of-hours care (overnight, weekend and public holidays).⁶⁵⁵

Some stakeholders expressed the view that more workers are needed on the floor of the nursing home, and less in administrative positions. For example, Reverend Stefan Slucki stated:

*Sufficient staff? On the wards, no. In the bureaucracy ... an over-abundance!... The term "Aged Care" covers now both 'nursing home' (high care) and 'hostel' (low care) residential as I knew it earlier in my ministry years. Most low-care elderly people are choosing to remain in their own homes—quite sensibly in my opinion, which means that institutional facilities are increasingly populated with exclusively high-care residents and I don't believe the staff-ratios have kept pace with these changes.*⁶⁵⁶

Similarly, a submitter whose name was withheld, stated 'Are there sufficient staff in the aged care sector to meet current and future workloads? No especially well trained carers. Too many chiefs not enough Indians'.⁶⁵⁷

A number of stakeholders stated that the number of staff in relation to patients should be dependent on the clinical care required and the needs of the residents. For example, Upper Mt Gravatt Wishart Catholic Parish submitted that there needs to be adequate staff to patient ratios at all times based on a person's care needs:

*There needs to be on-going assessment of residents to ensure that their care is being met as often they enter as low care but become high care as they grow older. As high care residents, they need greater personal care including showering and meal assistance and therefore staff to resident ratio needs to increase.*⁶⁵⁸

Similarly, Brisbane South PHN stated that appropriate staff provision (numbers, ratios patients to staff) is required, based on clinical requirement and level of patient ability/personal needs.⁶⁵⁹

Ms Vera Somerwil, National Seniors Australia Policy Advisory Group told the committee:

According to the evidence that we see from the royal commission—our executive officer from National Seniors has already presented evidence there—and the feedback raised by National Seniors members, the next of kin and all people who are involved are finding that lots to do with the aged-care system is actually substandard. More often than not, this is the result of inadequately trained staff and an insufficient staff. There is not enough time to attend to the social needs of the individual. They seem to be forgotten lately. As the carer of a person in an

⁶⁵³ Submission 2317, p 2.

⁶⁵⁴ Submission E738.

⁶⁵⁵ Submission 1207, attachment, p 3.

⁶⁵⁶ Submission 1680, pp 2-3.

⁶⁵⁷ Submission 2016, p 1.

⁶⁵⁸ Submission 1839, p 1.

⁶⁵⁹ Submission 1212, p 3.

aged-care facility for eight years, I can assure you that I have witnessed the shortcuts taken by staff and the lack of respect for the elderly...

*The skill mix of staff needs to be appropriate for different settings within aged care. Very frail and demented patients require greater nursing care than a resident with low-care needs—there is a difference you know—for activities of daily living such as feeding, bathing, dressing, toileting and social activities.*⁶⁶⁰

7.8.1.2 Staff qualifications and experience

Stakeholders also raised issues with the skill mix and care experience of staff in nursing homes, particularly in relation to the proportion of registered nurses to personal care workers.

COTA Queensland referred to the decrease in the proportion of skilled health professionals and the increase in personal care workers seen in facilities:

*Despite the increased age and frailty of aged care residents, in recent years there has been a decline in the number of skilled health professionals employed in facilities. Registered nurses made up just 14.9 per cent of the workforce in 2016 (down from 21.4 per cent in 2003). Enrolled nurses made up 7.6 per cent of the workforce (down from 14.4 per cent) and allied health professionals made up 1.1 per cent (down from 9.3 per cent). In contrast, semi-skilled personal care attendants accounted for 71.5 per cent of the workforce in 2016 (up from 56.5 per cent in 2003).*⁶⁶¹

Similarly, QNMU advised that in their audit of over eighty private sector aged care facilities in Queensland in May 2018, the QNMU found the staff and skill-mix of the aged care workforce has shifted to one where care is provided by unregulated care workers with Certificate III or IV qualifications rather than a regulated nursing workforce of RNs and ENs who have undertaken significantly more training. The QNMU audit found the average staffing and skill-mix percentages were RNs (16.02%), ENs (6.98%) and unregulated care workers (77.01%).⁶⁶² The QNMU stated:

*The decline in the number of RNs and ENs in aged care is well documented and unfortunately is occurring at the same time the care needs of those in residential care is increasing. As identified by Phillips et al., (2017) the proportion of those aged care residents requiring high levels of care has dramatically increased from 13% in 2009 to 61% in 2016 with aged care facilities increasingly acting as hospices for frail older Australians with complex care needs, yet with a workforce increasingly ill prepared to meet these needs.*⁶⁶³

AMA Queensland also expressed concern with the reduction in access and number of trained nurses reducing as a proportion of total staff involved in the facilities, stating:

*...this may lead to a lesser standard of care being provided to older Australians in these facilities. The latest data on the number of registered nurses in RACF had gone down from 21% in 2003 to 14.9% now. This decrease, which [was] also confirmed by Leading Aged Services Australia (LASA) during the Aged Care Royal Commission, corresponded with an increase in the number of personal care workers who have significantly less training an[d] background than trained nurses. Registered nurses should be involved in all stages of care for patients including clinical handover, ensuring prescriptions are actioned, managing emergency situations and in the provision of palliative care.*⁶⁶⁴

⁶⁶⁰ Public hearing transcript, Brisbane, 13 September 2019, p 11.

⁶⁶¹ Submission 1304, p 16.

⁶⁶² Submission 1213, p 11.

⁶⁶³ Submission 1213, p 11.

⁶⁶⁴ Submission 1233, p 1.

In addition to an increase in the number of staff, some submitters called for an increase in the number of experienced, qualified and registered staff.⁶⁶⁵

The QNMU referred to its 2018 audit, which they state:

clearly points to a situation where older Queenslanders are not receiving the standard and level of care they require in the residential setting. The findings of this audit identified:

- *care is largely provided by an unregulated aged care workforce ill prepared to meet the increasing health and aged care needs of those receiving services;*
- *missed care due to inadequate staffing and skill-mix means that residents are not receiving basic care needs in a timely manner putting them at greater risk of falls, pressure injuries and nutrition deficits.*⁶⁶⁶

The Royal Commission's interim report included discussion of evidence provided around a lack of training and qualifications of staff. It summarised:

*Much of the evidence to the Royal Commission indicates that, despite their best efforts, aged care workers and professionals too often have limited training and insufficient knowledge to do their jobs as well as they potentially might do. Workers are not trained in how to care for older people with the complex conditions that abound in aged care, such as the myriad forms of dementia or conditions which affect their physical and cognitive functioning. There is also a shortage of staff who are qualified and experienced in providing good palliative care.*⁶⁶⁷

The lack of staff trained and experienced in dealing with behavioural management, dementia and mental health issues was raised as a particular issue during this inquiry.⁶⁶⁸ For example, Ms Vera Somerwil, National Seniors Australia Policy Advisory Group stated 'With the increasing frailty of aged-care consumers, staff should have basic knowledge of how to look after people who have dementia, and I am afraid they do not'.⁶⁶⁹ Mr Keith Rickart noted that residents with dementia need to have one-to-one care with a dementia trained qualified carer.⁶⁷⁰

The QNMU advised that according to the AIHW (2017), approximately half of those receiving residential aged care have a diagnosis of dementia. However, the QNMU believes the current residential aged care workforce lacks the training and skills needed to adequately meet the care needs of this special needs group, with the situation compounded by the overall decreasing levels of RNs and ENs and resultant de-skilling of the workforce.⁶⁷¹

Many submitters expressed their view that more registered nurses need to be rostered at RACFs.⁶⁷² For example, Ms Margaret Johnson stated:

*It is imperative these nursing homes have better funding to enable an increase in trained and qualified staff to care for residents. They need registered nurses to monitor their declining health and be able to call on the doctors and specialists when needed in palliative care.*⁶⁷³

⁶⁶⁵ See, for example, submissions 1212, 2409.

⁶⁶⁶ Submission 1213, p 14.

⁶⁶⁷ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 222, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁶⁶⁸ Submission 1207, attachment, p 3.

⁶⁶⁹ Public hearing transcript, Brisbane, 13 September 2019, p 11.

⁶⁷⁰ Submission E911.

⁶⁷¹ Submission 1213, p 12.

⁶⁷² See, for example, submissions 1839, 2566, 2601.

⁶⁷³ Submission 2566, p 1.

Ms Faye Wright submitted 'These facilities must have sufficient qualified staff, especially Registered Nurses able to respond to acute problems with residents should they arise. Some situations require a higher ratio of staff to cope with the particular needs of a group of residents'.⁶⁷⁴

Mr Keith Rickart, a registered nurse, also supported an increase in the number of registered nurses, submitting:

*Its essential to increase the number of registered nurses on duty during all shifts in age care facilities to ensure quality of care. Only registered nurse[s] are trained to the required level to recognise and take the immediate required preventative action to maintain and enhance health and wellbeing of aged care facility residents.*⁶⁷⁵

PCQ addressed the lack of registered nurses on evening and night duty which they stated can cause problems if a resident deteriorates and needs clinical attention in the middle of the night, submitting:

*Without RNs on night duty, the default position is to have the resident transferred to hospital which would often be unnecessary if qualified staff (RNs) were on duty to make informed clinical decisions. PCQ has had reports of RACFs in Queensland who have one registered nurse available for over 100 residents. The clinical risks associated with such ratios is extremely high.*⁶⁷⁶

In particular, support for the introduction of minimum staff ratios was expressed by many stakeholders, particularly for residents with high needs.⁶⁷⁷

The QLS submitted:

*...unlike hospital or childcare settings, staffing in residential aged care settings is not subject to ratios. It is reported that without a mandated ratio the impact is seen directly in the reduced quality of care received by the residents. Insufficient Registered Nurse (RN)/Enrolled Nurse (EN) numbers therefore dictate that most care needs are being provided by the lower skilled and paid Personal Care Workers. An exception is where the facility is a state government owned property, for example Gannet House, Brighton. In these types of properties there is a requirement to comply with Queensland Health staffing regulations. A review of appropriate ratios should have regard to factors including acuity and skill mix as is necessary to ensure that appropriate care is provided.*⁶⁷⁸

The QNMU stated that to improve aged care delivery, mandated, evidence based staffing and skill-mix ratios in residential aged care are required.⁶⁷⁹ The QNMU argued:

A central tenet of the current ANMF Ratios for Aged Care Campaign is that significant and endemic staffing and skill-mix shortages have contributed significantly to the current "crisis" in aged care. This concern is reinforced by the research on staffing and skill-mix in residential aged care published by the ANMF in 2016 (Willis, et al). This research found that on average residents in aged care facilities required 4.3 hours of care per day with an optimum staffing and skill-mix of registered nurses (30%), enrolled nurses (20%) and unregulated care workers (50%). The research also found when these conditions were not present, there was increased likelihood of care being missed as well as increased risk and decreased safety for residents (falls, pressure injuries and nutritional deficits).

...

⁶⁷⁴ Submission 2539, p 2.

⁶⁷⁵ Submission E911.

⁶⁷⁶ Submission 1891, p 48.

⁶⁷⁷ See, for example, submissions E543, E911, E1693, 444, 1083, 2017, 2555.

⁶⁷⁸ Submission 1201, p 2.

⁶⁷⁹ Submission 1213, 23.

*As identified by the Senate Community Affairs References Committee Report Future of Australia's aged care sector workforce (2017) the requirements for the aged care workforce will increase from the current 366 000 to 980 000 by 2050 to meet the aged care demands of older Australians. Given the current shortfalls and projected demand it is essential that comprehensive measures to implement evidence based staffing and skill-mix are undertaken as a matter of urgency as well as broader workforce planning and development to meet future needs.*⁶⁸⁰

According to the QNMU, the following information provided recently to the Senate Community Affairs References Committee by the QNMU is relevant here:

- *Hospital avoidance is best achieved by having the right staff with the right skills and the right support to ensure timely treatment can be provided in the residential aged care facility;*
- *Hospital avoidance is best achieved through a well-coordinated multi-disciplinary team approach to care. However, the QNMU believes that the use of multi-disciplinary teams in the aged care setting is less than optimal. While the QNMU has a focus on nursing and carer staffing and skill-mix issues, the workforce issues associated with medical practitioners and allied health are also acknowledged;*
- *RNs and ENs are the only professionals who can oversee unregulated care workers (however titled) who are integral to the aged care team. They are professionally trained to lead and work within multidisciplinary models of care;*
- *Hospital avoidance is best achieved when all residential aged care facilities provide safe ratios of registered nurses and enrolled nurses, on site at all times in residential aged care facilities. This requirement must be enshrined in legislation for public protection.*⁶⁸¹

The Australian College of Nurse Practitioners called for RACF nursing ratios to 'support the higher care needs for these populations and remove the need to transfer residents out of their facilities to hospitals for end of life care'.⁶⁸²

Similarly, the Australian College of Nursing encouraged:

*...all governments at all jurisdictional levels to undertake policy reform which provides minimum safe RN staffing levels, and appropriate skills and 'skill-mix' in all health care settings, as well as urging the Australian Government to amend the Aged Care Act 1997 (Cth) to mandate safe staffing and 'skill-mix' levels.*⁶⁸³

The AMA stated it strongly supports minimal acceptable staff ratios to be introduced in line with the care needs of residents and ensuring on-site 24 hour registered nurse availability, with the acceptable staff ratio in residential aged care facilities being dependent 'on the level or number of patients with complex conditions in the facility at the time'.⁶⁸⁴

The QLS commented that implementation of minimum ratios for aged care staffing will not only increase quality of care for residents, but also reduce burnout amongst experienced staff.⁶⁸⁵

In terms of providing palliative care, PCQ advised that while there are currently no recommended or mandatory ratios for aged care, PCQ supports a policy framework that includes ratios to ensure the

⁶⁸⁰ Submission 1213, pp 16-17.

⁶⁸¹ Submission 1213, pp 19-20.

⁶⁸² Submission 1287, p 2.

⁶⁸³ Submission 1232, p 2.

⁶⁸⁴ Submission 1233, p 2.

⁶⁸⁵ Submission 1201, p 9.

safety of residents, and a significant increase in funding that supports better staffing ratios and recognises expertise and responsibility. PCQ stated:

Aged care requires the right skill mix and number of staff, available 24 hours a day to be able to respond to the palliative care needs of residents and consumers so they can be supported to have a high quality of life right to the end of life. Staff need time for clinical assessments and monitoring as well as adequate time to spend with residents which is not task oriented.

...

PCA is on the record as stating that the benefit of having ratios means predictability for staff in terms of rosters and a growing body of evidence that adequate nurse to resident ratios lead to better outcomes. The outcome PCA and PCQ seeks when discussing staff numbers, skill and mix is to ensure that a predictable standard of care is provided.

...

*This needs to include the staffing sufficient to ensure residents are able to receive palliative pain medication and symptom management at any time of the day or night.*⁶⁸⁶

Some submitters called for the same ratios to be applied to aged care that are currently applied in hospitals. For example, Ms Claudia Warren stated:

*There are not sufficient staff to resident ratio in the aged care sector. It needs to be the same patient: staff ratio as hospitals in some areas of high-care...On night shift, there should be 2 registered nurses working with the less-trained care staff, and a higher ratio also for day shifts and public holidays.*⁶⁸⁷

Ms Georgina Johansen advised that aged care is time demanding and most clients have high needs. She stated 'In comparison with hospital nursing staff ratio to patient, aged care is under staffed'.⁶⁸⁸

However, some stakeholders opposed the introduction of staff ratios. For example, HammondCare expressed concerns about staff ratios, submitting:

*Hammond Care's domestic cottage environment works best with a multi-skilled workforce structure; care workers are the 'eyes and ears' of the facility, while Registered Nurses are clinical leaders, teachers and enablers. Rigid staff ratios stifle such innovative models and evidence is inconclusive as to whether such ratios directly improve quality and safety outcomes for residents (COTA 2018, 28-30). However, literature does indicate that staff characteristics such as turnover, staffing levels, worker stability and agency staff should be addressed simultaneously to improve the quality of care being delivered in residential care facilities (Castle and Engberg, 2007). Consequently, Hammond Care maintains the view that the appropriateness of staffing levels should be assessed in the context of the service's philosophy, objectives and resident need.*⁶⁸⁹

As an alternative, Hammond Care suggested that the introduction of a minimum total care hours per resident per day could form part of the solution to improving transparency and information for aged care consumers. However, Hammond Care cautioned that this minimum should be developed in accordance with the care needs of defined resident groups, and would not on its own 'solve' the problem of poor quality care.⁶⁹⁰

⁶⁸⁶ Submission 1891, p 46.

⁶⁸⁷ Submission 2047, p 2.

⁶⁸⁸ Submission 2057, p 2.

⁶⁸⁹ Submission 1261, pp 5-6.

⁶⁹⁰ Submission 1261, p 6.

COTA Queensland also expressed the view that minimum staff ratios won't address issues in relation to staffing in residential care, submitting:

With aged care staffing in the public spotlight, there are questions about whether fixed ratios should be set to ensure minimum numbers of qualified staff. Along with COTA Australia, COTA Queensland argues that fixed, mandated ratios are not the answer to staffing in residential aged care. Mandated ratios cannot, on their own, resolve issues with staff quality and availability. In addition, staff ratios cannot address concerns about organisational culture or ensure that a particular resident will, on any day, receive a guaranteed number of hours of care.

COTA Queensland supports COTA Australia's call for four commitments about staffing in residential aged care: (1) staffing levels that are appropriate for the care needs of residents, (2) the requirement for service providers to publish their staffing levels, (3) for a registered nurse to be on staff at all times, and (4) mechanisms to ensure that qualified medical practitioners are available when required, including after hours.⁶⁹¹

One key issue highlighted by the Royal Commission is the competing demands on staff time and the resulting restricted time to care for patients. In 2016, the National Aged Care Staffing and Skills mix Project Report stated:

The current Aged Care Act 1997 indicates the numbers of care staff should be adequate to meet the assessed care needs – however, it provides no parameters on what the volume or skill mix of workers must be based on to safely meet the needs and care requirements of residents.

A growing body of national and international research and evidence clearly demonstrates that inadequate levels of qualified nursing staff leads to an increase in negative outcomes for those in their care, which results in increased costs.

In the acute setting, the implementation of safe mandated minimum staffing has been shown to prevent adverse incidents and outcomes, reduce mortality and prevent readmissions thereby cutting health care costs. It is widely agreed that the same improvements could be achieved in the aged care sector – but this is reliant on appropriate number and mix of skilled and experienced staff – which includes RNs, ENs, and assistants in nursing/PCWs. In the acute sector, two Australian states currently have legislated staffing levels and skills mix; and other states have mandated staffing levels (nurse to patient ratio or nursing/hours per patient day), ensuring transparency and are enforceable by industrial instruments. However, there has been little focus on the impact of nurse and personal care staffing and mix in aged care, with the exception of small scale studies.⁶⁹²

The Royal Commission stated:

The Royal Commission has heard in evidence that staffing is a critical element in ensuring the quality and safety of those in care. Services must have the right number of staff with the right skill mix, with compassion and empathy combined with knowledge of aged care and the illnesses and conditions of those in care. These are critical factors in delivering high quality and safe care to some of the most vulnerable people in our community.⁶⁹³

⁶⁹¹ Submission 1304, p 17.

⁶⁹² Australian Nursing and Midwifery Federation, National Aged Care Staffing and Skills Mix Project Report 2016, p 2, http://www.anmf.org.au/documents/reports/National_Aged_Care_Staffing_Skills_Mix_Project_Report_2016.pdf.

⁶⁹³ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 232.

7.8.1.3 *Personal examples*

The following extracts from submissions to the inquiry and evidence provided at the committee's public hearings highlight the impacts that short staffing in RACFs on the residents and staff.

Mr Jacob George: *My elderly mother who has paid taxes for the last 40 years is in an aged care facility. She is in the dementia ward at Cariniti Aged Care facility in Brookfield. She recently had a fall around 530 am, needed to be taken to hospital, had a CT scan and has extensive bruising. My mother was one of 15 residents in the dementia ward on the day she fell. Between 930 pm and 6 am, there is only one staff for 15 residents with dementia. I wrote and formally indicated this was unacceptable for a dementia facility, but management informed me that this was adequate. Clearly if patients are in a dementia ward and if they get up to go to the toilet (or for another reason), this is when they are at their most vulnerable (low blood pressure, disorientation etc). If they press the buzzer and a nurse attends, then for the other 14 residents, if they get up at this or similar time, the nurse will not be able to attend a second resident should the need arise. When I lodged a formal complaint, I was told that there is always a 'floater' that can help a second resident.*

This is not acceptable, patients with dementia have frontal lobe problems and are impulsive. This is the nature of the beast that is dementia. When they press a button and want a nurse, if a nurse does not arrive, they start walking and suffer a fall, that can be fatal. I see this all the time in my hospital. A floater will not be able to assist or come to the ward (there are 5 other wards), within the time frame required to prevent a fall (usually <1 minute). I have visited my mother on weekends at 7 pm when there are more staff on the ward. When I press the button to have the front door opened, it takes a minimum of 3-5 minutes and several rings before they answer (no doubt because they are busy). Thus, it is a fallacy to state that a 'floater' can come and help an impulsive resident with dementia in an acceptable timeframe. I find it unacceptable that elderly vulnerable residents that have paid 40 years of taxes are not given the best care. There MUST BE STAFFING RATIOS FOR THE FULL 24 HOURS, more so in dementia wards. Aged care facilities should be run for the benefit of residents, while profit and cutting costs is not acceptable.⁶⁹⁴

Mr A C Lynn: *One of the more inhumane ways is to have dementia and be warehoused in an understaffed nursing home -- in other words, any nursing home in a regional area as all seem to be understaffed. Most of the staff and management are decent human beings and many sincerely care, but they are working in an almost impossible situation. Realistically the staffing situation is likely even worse than any "quality of care" statistics might indicate as the nursing/healthcare qualified management and administrative staff may be included as part of the face-to-face resident care staff. And then the "therapy nurse" (previously known as activity coordinator) routinely gets shunted into kitchen and cleaning duties whenever one of the general staff calls in sick as no one else knows the food preparation duties.*

My wife rightly calls the process "incarceration" and if I didn't continue to provide personalised care, both within the nursing home and taking her out, 12-30 hours per week she would at best receive 4 hours per week of personal contact beyond toileting, dressing and wheelchairs to/from meals. For us personally the situation could be worse (and was).⁶⁹⁵

Ms Susan Eggington: *I have recently been doing voluntary work at an Aged Care Centre on Bribie Island. I also have recently completed a Certificate III in Aged Care and did 3 weeks full time work experience at the same Aged Care Centre. During this time I saw and experienced a lot of what occurred in the nursing home and can only presume that it is similar to other homes. I found the rooms to be very small and dingy, a lot of the residents were very unhappy and depressed. The major problem was the lack of staff, because they have such a heavy work load they are unable*

⁶⁹⁴ Submission 1358, p 1.

⁶⁹⁵ Submission E1578.

to spend the time needed with the residents. The daily care tasks are often rushed because of this. Some residents are waiting for ages to go to the toilet, to have their continence aids changed etc and this causes them a lot of stress. I spent a lot of my time, comforting residents who were upset because of lack of care, because of rudeness of some of the nursing staff towards them. The food was horrible, overcooked and not tasting good, most of the residents didn't like it and often just asked for toast instead. This was a good aged care centre, there was no abuse of residents, they had good programs, they had a good reputation, the place was clean, they had activities, they had some lovely staff, and volunteers but still it wasn't enough. High care and dementia patients just need so much attention and work and there is just not enough staff to attend to their needs adequately. The residents who are mobile and have access to friends and family, have a much easier and enjoyable time as they can do things independently, but the residents who are in wheelchairs or princess beds who are unable to mobilise are completely helpless and totally reliant on the staff. When there are 2 staff on duty, dealing with a resident who requires 2 staff members to change them or shower them, then there are no staff members available to deal with anyone else who needs it, so they have to wait. Say they need to go to the toilet, they can't go by themselves, if they can't wait too long, then they have to do it in their pads, or in the bed and sit in the mess until staff are free. At night time, there is usually only 1 staff member on duty, same problem again, if they are helping a resident then others just have to wait and in some cases, that is just unacceptable.

Dementia and other high care residents can sometimes be in a terrible state, unable to speak, unable to move, unable to feed themselves, unable to communicate, wearing a pad, having others wipe their bottoms, and dress them and feed them. No one that I know would ever want to be in that situation, they hate it and it is very very sad. If they were a dog, they would be put down out of their misery but no, our society makes them suffer and go on suffering for year and years. Often people have no families that come to visit them, they are dying of loneliness and sadness and it is a terrible thing to witness. The most important need for residents in nursing homes are more staff, trained and caring staff that have the time to care for them properly. They don't need more nurses, it is in the daily cares, the daily tasks, showering, dressing, feeding, toileting, changing, activities, socialising etc that they need more assistance.⁶⁹⁶

Ms Carol Single: *The Queensland government must ensure that staff-to-resident ratios are put in law. The current inadequate staffing levels are determined by Good Shepherd Lodge, and it is not providing a safe level of care 24/7. ... My mother, Ruth Brooks, moved to Good Shepherd Lodge in December 2009. ... January 15: Ruth fell again, breaking her right knee and left arm. I witnessed her leg brace on the wrong leg. The arm sling and leg brace were not fitted correctly on most occasions—it was around her back, rather than supporting her arm. I saw staff trying to lift her off the bed to shower her who did not even know she had a broken arm. Staff had zero knowledge and training to fit medical aids.*

November 16: Ruth's foot was red and infected. She was usually showered about 5.30 am and the wet bandage on her foot was not changed until lunchtime, as there was no RN available early to do the dressing.

January 18: I walked in at about 6.30 in the morning and from the other end of the building I heard a blood-curdling scream coming from a lady: 'Help, help, help!' She was terrified. I went looking for staff but I could find nobody. This lady was falling off her bed, drenched in urine and faeces and shivering. There was no staff to assist. I wrapped a blanket around her and pushed the buzzer but still no-one came. There were only two aides in nursing on shift that whole night for 43 residents. Half of those residents are in Eurobeds and wheelchairs, needing two staff to lift them at any time. If there are not enough staff, which there was not that night—apparently they tried to call other staff in but none were available—they are just left in their rooms,

⁶⁹⁶ Submission E1600.

*sometimes for days or weeks at a time, with the door closed like caged animals, and on weekends that is where they stay. They all stay in their rooms. November 18: she had a fall and had massive bruising down her face. I was advised that her eye was red, not that it had haemorrhaged, requiring urgent specialist assessment and CT scan. February 19: she had fungal toes. You get the picture. It makes me ill. The podiatrist who had been treating her for the year advised that many residents had fungus and that they were not worth treating. The toenail was bigger than a quarter of an inch high, with virtually pus coming out of it. I am so saddened for any resident without family who cannot speak up for them or who is totally bedridden.*⁶⁹⁷

Ms Carol Single: *I have a girlfriend in Good Shepherd Lodge whose mother has been there the same time as my mum. They are both around 97. She has a colostomy bag. It has overflowed several times, burning her really badly. Some of her skin is now just black blobs. There are staff who do not even know she has a bag. Her daughters—one is an intensive care nurse at the Mater—come in three times every single day to check she is okay. That is how they feel. The other 20 people who are in the evolution beds, euro beds—a lot of them do not have anyone to check on them. If it is Easter, on the Thursday afternoon at three o'clock the diversional therapists go home. There is nobody to assist feeding these people. They are there in their rooms all day Friday, Saturday, Sunday and Monday and the diversional therapists come back Tuesday.*

*We have been told we cannot help feed other residents. There is a lady at my mum's table and often I encourage her to try and eat and assist her. What should we do? Just sit there and let them starve because there is not enough staff to feed all those people? I am not going to do that. I am told that if she chokes it is my problem, that I will be the one liable. Should we let them starve for the next years that they are there?*⁶⁹⁸

Ms Janet Corcoran: *My husband has been in there for the past 15 months. I have become a volunteer, but I am a volunteer for my own protection and for them. They have two lounges and two kitchens instead of one big dining room and one big lounge room where all the staff can look after them. We have a split-up of two dining rooms, two lounge rooms and no staff supervising. Half the time there is not enough staff at the place for safety or to watch these people who need watching. I have come across quite a few falls or helped someone who is falling. If I hear someone screaming out or something, because my husband is near a lounge, I will go in and just check, because I know they are unsupervised.*

*I am there for my own husband. The staff are completely worn out. They were nice and friendly, but now they are not as smiley and they are grumpier because they do not have the staff to replace them. They are working hard. I appreciate what they do, but they need education, training and support. I presume this would happen in a lot of nursing homes. The people there are paying good money to be in the nursing home. They need protection. They need the staff. It is a privately owned nursing home. A couple of weeks ago the stores were locked. There were no wipes in there. I am noticing little things like that. I have waste bags in my room for my husband's disability, because he has no dignity at all. When you go in and say that your husband has a stoma and it has been put on upside down, where is the problem going to go to? Who is going to fix it up? Who is going to clean it? It is going to be me, but it is not fair for him. Education is a big thing in these nursing homes, because the staff are run off their feet. There is a shortage and I think something needs to be done about it. The staff are telling me, because I will speak up.*⁶⁹⁹

Ms Deborah Frugtniet: *I can only speak from our experience and that of those that we have been in touch with in the same facility, but unfortunately the care is nothing short of neglect at times. I compare it to our young people in child care and the ratios that they are given, the requirements*

⁶⁹⁷ Public hearing transcript, Mackay, 29 October 2019, pp 9-10.

⁶⁹⁸ Public hearing transcript, Mackay, 29 October 2019, p 15.

⁶⁹⁹ Public hearing transcript, Cairns, 27 May 2019, pp 24-25.

for dietary nutrition, the requirements for reporting and the communication. I cannot see any comparison between the elderly and young people in terms of the standards being the same. In my eyes, these people at 80-plus with high-care dementia, or even younger unfortunately, are neglected.

We have seen things like dad being bedridden, but he has bed sores because he is not turned enough. We were late for today's meeting because mum was with dad because he was having a seizure. When mum said to the RN, 'What is going on here?' she said, 'That's because he hasn't been turned.' He had not been turned for 24 hours. We have had to write the time on the back of dad's nappy pants to prove that they are not being changed. I have had to insist on his bed being changed because it was filthy. Mum has to take food up. Mum is 70-plus years old. She is up there for 16 hours a day sometimes because there are not enough staff.

We have just had Earle Haven—the walkout at Earle Haven. Two nights later we were in a very similar situation. Other patients' families were there and were refusing to leave because there were two people to care for 40-plus high-care dementia patients. I waited for an hour to help dad get to the bathroom because we cannot do it on our own. In that time they had another patient next door on the toilet and they are saying, 'Just stay. Just stay,' because they could not be in two places at once. This is not okay for our elderly.⁷⁰⁰

Ms Gail Thorpe: *I have had a couple of good friends recently in aged care. There are a few points that I want to bring forward. Staff ratios are long overdue. Having two so-called nurses or carers with minimal training for 25 elderly, vulnerable patients is disgusting. The care is not care. It is a do-not-care place. That is one thing.*

Not having an RN on at night is absolutely terrible. My colleague goes home at night expecting to be called by, again, so-called nurses. There is some training. There are AINs and ENs, but that is it. She expects to be phoned up about things or to be called out. The whole nursing home has nobody at registered nurse level. That is a very poor thing. I think that if the relatives were aware of that, they would be as disgusted as I was when I heard it. Unfortunately, frequent errors are made in aged-care residences because, again, of the low standard of staff. Having worked in hospitals for years, we expect a standard for patients in care and residents should be afforded the same level of care.

Wrong patients are seen. For example, my friend was woken up in the middle of the night. There was a man standing next to her bed. My friend was 90 but as sharp as a tack. The nurse came with him. He did not introduce himself. She did not know who he was. He said, 'How are you?' She said, 'I'm fine.' 'Good,' he said, and wrote something down and they both went. The next day she had an extra tablet in her little tablets that she was given. She said, 'What's this?' They said, 'It's your antibiotic for your chest infection.' She said, 'I don't have a chest infection.' Through investigation she found out that it was for the patient next door and the doctor should have been visiting the person next door. The nurse had not taken the time to even identify the patient, let alone the doctor, who had not introduced himself, or Rita would have said, 'I'm not her.' This sort of thing happens over and over again. I have witnessed a tablet being so-called dissolved in water, when it was enteric coated and was not dissolvable, by a nurse who did not know what he was doing. The blister packs are set up by an RN and given to people with very little training, or no training. They just dish them out as they go along the ward. It is in great need of an overview.

There is a massive gap between the aspiration, the ideals of palliative care and its reality. We only have to have relatives like I have had recently—in the last 20 years—going through palliative care to see that. Many patients in palliative care are still suffering day by day, even though I have been told time and time again, 'This is 2019. They should not be suffering. They should not have

⁷⁰⁰ Public hearing transcript, Southport, 10 September 2019, p 44.

pain. We should be able to do something for them.’ It is very distressing to sit next to someone for four days and see them dying. Many people here have had that experience and I have recently. My friend went into intermittent agitation. I was told, ‘As soon as she becomes agitated, come and get the nurses and they will come.’ Half an hour later they came. In the meantime the agitation had become really high and I was told, ‘Sorry, we got held up with somebody else.’ There is a lot more that I could say.⁷⁰¹

Mrs Michelle Williams: *My mother has been in this residence for five years. She was fairly independent when she went there. In the middle of 2017 her health started to deteriorate due to a change from the governance of the home into a corporate affair and the whole place just went downhill—with funding, with staffing and all sorts of things that were happening. When her health started deteriorating in 2017, she started suffering from paranoia and was diagnosed with oedema, resulting in her legs swelling, and she became unable to move around or toilet herself properly. Unfortunately, because of the neglect and the lack of proper training and care from staff, she has had several hospitalisations from 2017 to 2018 in regard to things that could have been easily prevented. She has also had hospitalisations again this year—things like being overdosed on oxygen because the nurse did not know how much he should give her because she had CLAD and he did not understand so he just pumped her up with oxygen, which sent her into having a terrible time and she had three weeks with delirium. They sent her to two different hospitals to try to control the delirium. When she was finally sent back to St Mary’s—excuse me, I should not have said the name—it was discovered that is what it was. There was no apology; there was nothing to say anything about this nurse. All I was told was, ‘We’ll have to train the nurses properly.’ That is just one instance.*

The other instances that have happened to my mother, as I said, could have been easily prevented. My mother was classified as a really high fall risk. She had a massive head injury in the beginning of 2018 from being left in a toilet by herself after I was absolutely guaranteed that she would never be left alone anywhere, particularly on a toilet. That turned into a massive head wound that was not treated by the staff properly and was not treated by the doctor out there. This resulted in a scab being on her head for several weeks until the smell became that bad that we took her to another doctor outside who diagnosed it just through the fact that it was matted blood and hair on her head. I even had to beg the nurse one day to wash her and clean her hair up from the blood that was dribbling constantly down her head because they never put any dressing on it. It was easily fixed within 10 days of us going to see another doctor. We ourselves bought the medications for it and we fixed it. We have never divulged that doctor’s name because she said it’s against their whatever it is, so we cannot divulge it. I respect her completely for that. I would not tell the centre. They got quite upset that we would not tell them what happened. From the moment we started treating that ourselves as a family, that wound healed. That upset us greatly. The next thing I know, my mother had her oedema come back in her legs after repeatedly asking them to please do something about the oedema. It is not an easy thing to fix, but the most important thing is they get fluid tablets to fix this. It just did not happen so she was once again hospitalised for two weeks over that.

Once again, they had a change of management at the centre and it seemed to pick up a little bit, except they then decided to put tubing on my mother’s legs. They were incorrectly put on by the nurses and staff and it resulted in her knees swelling. Nobody took any notice of that and they kept telling me it was in my head. Finally, the physio confirmed with me that the reason her knees were swelling up was that the tubing was too tight. They then decided they would get somebody in from the head office staff to sort it out, which they did, which I was very grateful for, because

⁷⁰¹ Public hearing transcript, Brisbane, 13 September 2019, p 72.

*that became more important to her. In February this year, as I said, she was given too much oxygen and she was once again hospitalised and she went into this thing.*⁷⁰²

Stakeholders also provided examples of the impact that staffing levels and mix have on the staff in RACFs:

Ms Helen Arthur: *I have a friend who is a mature age, Aged Care Registered Nurse.*

She is terrified to say anything to anyone for fear of retribution aimed at whistle blowers. As a single woman paying a mortgage she cannot afford to lose her position. It is already apparent that she loses shifts to younger workers who are paid considerably less per hour.

My friend is regularly in charge of up to 36 residents in one facility and up to 44 residents in another facility. It is almost impossible for her to attend to all of the residents needs during the shift. She must dispense medicine, attend to wounds and dressings as well as be available to assist doctors when they need to be called for more serious situations.

Because my friend loves her job and her residents, she puts every effort into doing the job which she sees as a privilege rather than work. As a result of her diligence, she has been reprimanded by her employer for not getting all her work done inside the shift time frame. She is required to complete all relevant paperwork inside the shift as well. Her employer will not pay her overtime if she needs to work one or two more hours to complete resident needs. To add insult to injury, her shifts are altered on short notice, which makes her life very difficult.

She is regularly called on by junior staff to provide her opinion and her assistance, when they have no idea how to assist the resident or if supplies of hygiene pads or other necessary equipment is unavailable.

*My concern is primarily for my friend, who is working herself into an early grave because the facilities in which she is employed do not have anywhere near the correct number of staff as a ratio to numbers of residents.*⁷⁰³

Name withheld: *I'm a registered nurse and I worked in aged care for a while and it's hard to put into words that fear that I had on the way to work knowing the patient to staff ratios that I would be under. I was terrified of making medication errors or not escalating a health concern soon enough or not getting time to do a wound dressing. And I wasn't the only one. I was the lucky one who got to move my career to a hospital where I am protected by safe ratios. The unlucky ones are left in aged care torn between doing what they love and not having the resources to be the sort of nurse they need to be. No amount of time organization makes up for the time it takes to respond to deterioration in your residents which leaves residents vulnerable to medical errors and left with minimal contact time and it's wearing down nurses to the point of them wanting to quit. The aged care industry is killing respect for elders and it's killing the nurses who are trying to provide decent care within this system.*⁷⁰⁴

7.8.2 Quality of personal care

The quality of care received in RACFs was raised as an issue, and was closely associated with staffing levels, experience and training, as well as resourcing of the RACF and a lack of proper oversight.

In their submission, LASA advised that it considers that the majority of providers meet the recognised standards in aged care, with many providers going beyond these minimum standards, in providing high quality, consumer focused care.⁷⁰⁵

⁷⁰² Public hearing transcript, Ipswich, 9 September 2019, pp 31-32.

⁷⁰³ Submission 2110, p 1.

⁷⁰⁴ Submission E104.

⁷⁰⁵ Submission 1283, attachment, p 2.

LASA stated:

...a number of key reports have found that the majority of older Australians accessing the aged care system receive good quality care. These include various international comparisons along with data from the 2015 Australian Bureau of Statistics Survey of Disability Ageing and Carers reported by the Productivity Commission which indicates that:

- *of those people aged 65 years or over who reported a need for, or received formal services in the previous six months, 76.1 per cent were satisfied with the range of services available; and*
- *of those people aged 65 years or over who received formal services in the previous six months, 89.2 per cent were satisfied with the quality of assistance they received.*

This is also similar to the findings from the Consumer Experience Reports undertaken by the then Australian Aged Care Quality Agency in 2017-18, which found that approximately 91.7 per cent of residential care residents (or their representatives) regarded the facility as well run.

However, LASA also acknowledged that there have been ‘instances of unacceptable failures in care’, referring to ‘recent year on year increases in complaints to the Aged Care Quality Commissioner’. LASA advised there has been an increase in instances of provider non-compliance with the aged care quality standards, as assessed by the Australian Aged Care Quality Agency.

LASA attributed this to resource constraints and difficulties in recruiting a suitable workforce.⁷⁰⁶ LASA stated:

*The responsibility for many reported instances of substandard care, mistreatment or abuse lies directly with individual employees and/or their organisations. There are also though, system issues which inhibit the ability of providers and individual care givers to offer older Australians the care they deserve. Despite the funding pressure that they are under, providers have continued to increase the number of hours of care per resident, but this cannot continue indefinitely, and some providers have reported that they are already being forced to cut back on staffing.*⁷⁰⁷

In contrast, ADA Australia submitted that the quality of the care provided is perhaps the most common concern raised through advocacy case work in residential care. ADA Australia advised that quality of care concerns typically include:

- *slow response times when residents request help*
- *poor hygiene management including infrequent showers, continence aids left soiled, teeth not brushed etc*
- *the quality of food and lack of support for those requiring assistance to eat food*
- *clinical care concerns including:*
 - *inadequate hydration and nutrition*
 - *conditions undiagnosed until they have reached a critical stage and hospital admission is required*
 - *wound care - particularly in relation to the prevention, identification and management of pressure wounds*
 - *chemical restraint – often used as a behaviour management strategy before other less restrictive options have been explored. Decisions are often made with consultation with family members/representatives*

⁷⁰⁶ Submission 1283, attachment, p 2.

⁷⁰⁷ Submission 1283, attachment, pp 6-7.

- *poor medication administration/management.*⁷⁰⁸

The QNMU also expressed concern that older Queenslanders are not receiving the quality of care they need. The QNMU audit of residential aged care in 2018 identified significant concerns regarding missed care driven by what the QNMU considers to be understaffing. Audit respondents identified the following issues which QNMU believes points to significant quality of care, staffing and skill-mix issues:⁷⁰⁹

Table 15: Issues identified by audit respondents

Missed care issue	Percentage
Residents waiting longer than they should when they ask for assistance/help	80.49%
Not enough time to complete hygiene cares for residents	68.29%
Residents not being repositioned as often as needed	62.20%
Residents not being mobilised as often as needed	60.98%
Increased falls	57.32%
Not enough time to properly feed residents	57.32%
Not enough time to document care	51.22%
Other response or comment (please specify)	48.78%
No time for shift handover	47.56%
Increased pressure injuries	40.24%
Not enough time to attend/complete wound care	34.15%
Increased skin tears	31.71%
Medications being missed or not given at the right time	26.83%

Source: Queensland Nurses and Midwives Union, Submission 1213.

Other submitters provided personal examples of inadequate care. For example, Ms Elsie May Geaney referred to her experience of a nursing home where:

- *...they allow funds for 3 disposable pants a day, and that is all you are changed unless family are there to do it and provide the extra pants needed. Strange isn't [sic] it. Where as a mother who only changed a baby 3 times a day would be up for neglect.*
- *Food is shovelled into your mouth if you can't feed yourself as staff are so short of time.*
- *You share a room with others who have conditions worse than you, ie yell and scream continually, so you despair at your future and hope you die soon.*⁷¹⁰

Another submitter, who requested her name be withheld, told the committee:

My husband has had dementia for almost five years. I looked after him at home for as long as I could, but had to put him in a nursing home for the last 12 months.

He is incontinent, unable to feed or bath himself. He is just wiped over every second day and a shower every other day. It is just so hard for me to see him the way he is. I spend at least two hours every day feeding him his lunch.

⁷⁰⁸ Submission 1243, pp 3-4.

⁷⁰⁹ Submission 1213, p 12.

⁷¹⁰ Submission 230, p 1.

*He can't sit up because he has a collapsed spine. He can't talk to me. He is unable to request simple things like a drink of water and not enough staff to make sure he gets one. He is allowed three only napkins to wear each day for his incontinence. I believe the care he is receiving is a result of not enough staff. I pay \$900 per week to keep my husband like this.*⁷¹¹

Dr David McFarlane advised of needing to constantly monitor the care provided to his mother and the impact this had on his time with his mother:

*As many relatives and friends said the only way to keep the facility on point was to be polite – but have a foot on the 'throat' at all times....My parents were probably fortunate that at least two sons always present to engage with management, and two physicians present in the family. Cynically this is probably the main reason for care being of a reasonable standard, but having to be always on watch deprived me from spending time with my mother as a son during her last months of life. I will try and forgive, but cannot forget.*⁷¹²

Pain management in RACFs was raised as a particular issue. The Cancer Council Qld informed the committee that pain management is a frequently reported issue for clients with family members in RACFs. According to the Cancer Council Qld, over half of callers to the PalAssist service in 2018 were carers (13.3%) or family/friends (48.5%), many of whom expressed concerns about the pain and suffering of patients.⁷¹³

The ANZSGM stated:

*Clinicians should have access to training and have adequate skills to assess and manage pain in an ageing population. Documentation of pain should be routine in all facilities caring for older people, with self-reporting the gold standard. Observational and behavioural scales should be employed for individuals unable to reliably report pain due to cognitive or communication deficits.*⁷¹⁴

Similar to QNMU's concerns about the role staffing plays in the quality of the care provided, ADA Australia advised that consumers, carers, family members and representatives' advocates work with often cite inadequate staffing as the underlying issue in quality of care concerns. References to inadequate staffing often encompass inadequate staff numbers, a lack of skilled staff/regulated workers, inadequate supervision and poor organisational culture.⁷¹⁵

The QLS submitted that the quality of services received in RACFs are inconsistent, despite quality inspections and accreditations, and that clients regularly report continuing falls, neglect of personal care needs, and limited to no flexibility within a facility's routine. They stated this is impacted by several issues, including 'quality of staff, staff numbers, staff experience and training. Clients often request specific staff members based on their compassion and ability to care appropriately'.⁷¹⁶

Queensland PHNs advised that nurses in RACFs have suggested peer support strategies such as an 1800 number that can be called day or night when they are on their own, and could benefit from the advice and support from an experienced colleague. However Queensland PHNs also pointed out that improving the clinical care in RACFs cannot be achieved by the facilities alone, and suggested that collaboration across aged care, primary health care and tertiary healthcare services is required and PHNs could be effective mechanisms to facilitate this.⁷¹⁷

⁷¹¹ Submission 446, p 1.

⁷¹² Submission E1634.

⁷¹³ Submission 1303, attachment, p 3.

⁷¹⁴ Submission 1720, p 3.

⁷¹⁵ Submission 1243, p 4.

⁷¹⁶ Submission 1201, p 5.

⁷¹⁷ Submission 1301, pp 6-7.

Submitters also contended that better oversight is required. Brisbane South PHN expressed the view that more efficient reporting processes are required that focus on key aspects (indicators) of delivering quality care, while Ms Erika Gerdson suggested there's not enough follow-up or consequences when aged care providers are found to be lacking in their care.⁷¹⁸

7.8.3 Meal times

Stakeholders also raised concerns about the amount and quality of food served to people in RACFs.⁷¹⁹

Dr David McFarlane stated that in his experience the food offered to his relative was limited in choice, and there were no fresh fruit or vegetables, with the menu set months in advance by head office.⁷²⁰

Mr Keith Rickart proposed that meals in aged care facilities need to be designed by a nutritionist and prepared on-site containing all required food groups and be presented in such a way to facilitate residents' ability to feed themselves.⁷²¹

The QLS advised that:

*Studies have found that spending on food in RACFs has declined in 2016/17 in comparison to previous years' data. This is consistent with achievement of lower profit margins, which is seen to put pressure on the costs of food and food management. Clients have reported concerning trends such as that, 'Sunday nights are the worst meals because there's no visitors around then.', and that meals might consist of just two party pies or sausage rolls.*⁷²²

The QLS also advised that clients have told them that staff, mostly personal care workers, do not have sufficient time to assist each resident to eat, resulting in poor nutrition outcomes for many residents. Clients who require considerable assistance are seen to first, and it is reported that others who require minimal assistance are not seen to as regularly. The QLS referred to the following research which states:

*Malnutrition is associated with a cascade of adverse outcomes, including increased risk of falls, pressure injuries and hospital admissions, leading to poorer resident quality of life and increased health care costs... Diminished sensory perception along with the physiology of ageing may increase malnutrition risk.*⁷²³

On the matter of food, the QLS also noted that dementia based nutrition research indicates that a variety of meal time strategies can be implemented to improve residents' nutrition and functioning, however these rely on appropriately trained and qualified staff.⁷²⁴

7.8.4 Restrictive practices

A number of stakeholders raised the issue of using restrictive practices on those in RACFs, particularly older people with dementia.

AMA Queensland called for the use of physical and chemical restraints to be limited, and used as a last resort, stating:

Sadly, however, they are sometimes used in situations when the patient is at risk of harming themselves, staff or other residents. This includes behaviours such as aggressive yelling, throwing

⁷¹⁸ Submission 1212, p 4, Submission 1642, p 2.

⁷¹⁹ See, for example, submissions E252, E911, E1309, E1634.

⁷²⁰ Submission E1634.

⁷²¹ Submission E911.

⁷²² Submission 1201, p 3.

⁷²³ Cherie Hugo, Elisabeth Isenring, David Sinclair and Ekta Agarwal, 'What does it cost to feed aged care residents in Australia?', *Nutrition & Dietetics* 2018; 75, pp 6–10, in submission 1201, p 4.

⁷²⁴ Submission 1201, p 4.

*food and other items at staff and/or other residents or spitting and hitting others. For the attending General Practitioner, it is important to understand whether there is a clinical reason the patient is behaving in this manner, such as an infection or deteriorating mental health.*⁷²⁵

AASW Qld Branch told the committee:

*For people living with dementia, issues around restraint are ongoing, whether it be medical or physical restraints to manage behaviours viewed as undesirable. The use of restraint can be impacted by staffing levels, lack of appropriate training, use of agency staff unfamiliar with the client's needs and inappropriate living environments.*⁷²⁶

QLS advised that restrictive practices in aged care are unregulated and unreported, and that while the Australian government has recently released guidelines for chemical and physical restraint use in aged care,⁷²⁷ the QLS believes the guidelines don't go far enough.⁷²⁸ The QLS submitted:

While its stated goal is to achieve the minimised use of such restraints, it is the Society's view that it does not go far enough to provide a patient with sufficient opportunities to refuse the imposition of these practices, nor the substitute or supported decision-maker.

*QLS is concerned that the introduction of guidelines which enable the use of these practices in the absence of adequate consent considerations in relation to the affected resident and without a robust overview framework, will have the opposite effect, particularly in light of issues around capacity. This will be seen to rubber stamp an existing practice which is inconsistently applied and if insufficiently regulated, presents a risk to a vulnerable cohort of our aged population.*⁷²⁹

The Public Advocate commented on the recent 'strengthening' of the Quality of Care Principles, stating:

While any tightening of the standards of care around the use of physical and chemical restraint are supported, the proposed amendment does not adopt many of the fundamental features of an accountable and transparent restrictive practices regulatory framework as recommended by the Australian Law Reform Commission in its report, Elder Abuse — A National Legal Response.

...

The approach that the Australian Government has taken to the issue of regulation of restrictive practices in residential aged care demonstrates a complete lack of knowledge and understanding of three key issues:

- *the previous reviews and recommendations about restrictive practices in aged care that have been undertaken;*

⁷²⁵ Submission 1233, p 5.

⁷²⁶ Submission 1288, p 13.

⁷²⁷ A new single set of quality standards applicable across aged care service types has replaced existing standards, with the Aged Care Quality and Safety Commission publishing *Guidance and Resources for Providers to Support the Aged Care Quality Standards*, 2019, which includes guidance on demonstrating compliance with standards concerning minimisation of restraint. The *Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019* will impose obligations on providers that include ensuring that an assessment is carried out by a health practitioner who has concluded that restraint is required and that the reasons for the restraint and any alternatives to restraint that have been used are documented in the resident's care and services plan. The provider must regularly monitor the resident for signs of distress or harm while the resident is subject to the restraint.

⁷²⁸ Submission 1201, p 5.

⁷²⁹ Submission 1201, p 2.

- *the law that applies to the use of restrictive practices and of basic legal and human rights; and*
- *the principles of positive behaviour support which should underpin any approach to restrictive practices, and yet, is not mentioned in the Aged Care Act 1997, the Principles or Standards or any of the supporting resource material provided by government.*⁷³⁰

*Ultimately, the new measures announced by Minister Wyatt do not establish the legal framework required to lawfully permit and regulate the use of restrictive practise in residential aged care facilities.*⁷³¹

The Public Advocate recommended the Queensland Government advocate for the Australian Government to immediately implement a comprehensive residential aged care restrictive practices regulatory framework with all of the characteristics and protections recommended by the Australian Law Reform Commission in its report *Elder Abuse – A National Legal Response* in Recommendations 4-10 and 4-11.⁷³²

The Public Advocate also raised the commencement of Queensland's *Human Rights Act 2019*, stating:

While it is questionable whether the Act will apply to residential aged care facilities, it will definitely apply to residential aged care facilities operating in Queensland under the auspices of Queensland Health. Consequently, the use of restrictive practices in these facilities without informed consent may be in breach of the Human Rights Act 2019.

*With this in mind, the Inquiry should consider recommending that, failing the Australian Government acting to properly regulate restrictive practices in residential aged care, the Queensland Government adopt a restrictive practice regime similar to that under the Disability Services Act 2006 for State-operated aged care facilities.*⁷³³

Mr Roger Moloney provided a personal example and argued that restrictive practices need better regulation:

*Chemical restraints on aged care facility residents needs to be reviewed. My Father was discharged from hospital and prescribed fentanyl patches for pain. He experienced hallucinations from this medication and it impacted on his wellbeing and dementia. Despite his family doctor recommending he cease the medication the facility care managed argued that my Father maintain this medication. I eventually managed to stop this medication and my Father's condition improved significant [sic] and his pain was adequately managed with paracetamol. Medication that has a 'dual purpose' such as fentanyl must be better regulated in aged care facilities eg beyond a short period reviewed by specialist doctor/QLD Health.*⁷³⁴

In her submission to the inquiry, the Public Advocate explained:

*... the law governing these practices in residential aged care is unclear and, for the most part, non-existent. The Aged Care Act 1997 (Cth) does not formally regulate the use of restrictive practices in residential aged care facilities.*⁷³⁵

⁷³⁰ Submission 1208, pp 4-5.

⁷³¹ Submission 1208, pp 4-5.

⁷³² Submission 1208, p 5.

⁷³³ Submission 1208, p 6.

⁷³⁴ Submission E842.

⁷³⁵ Submission 1208, p 4.

The Public Advocate acknowledged that there was some regulation of restrictive practices in Queensland in part 6 of the *Disability Services Act 2006* and chapter 8 of the *Mental Health Act 2016*.⁷³⁶

Restrictive practices was an important area of concern of the Royal Commission. In its interim report, the Royal Commission stated:

*People do not surrender their rights to mobility, personal autonomy, legal capacity and dignity when they enter residential aged care. The prevalence of restrictive practices in residential aged care is unacceptable. The Royal Commission can only conclude, on the evidence before us, that the ongoing and common use of restrictive practices in aged care represents severely substandard and unsafe care.*⁷³⁷

In its interim report, the Royal Commission particularly denounced the current use of psychotropic medication, stating:

*While it is difficult to ascertain the precise extent to which the prevalence of psychotropic medication dispensing correlates with the use of chemical restraint, it appears that prescription rates for people in residential aged care are significant and well above what might be expected. In 2019, the Australian Government's Aged Care Clinical Advisory Panel, comprised of experts from across the health and aged care sectors, estimated that only about 10% of antipsychotics medications and benzodiazepines used in residential aged care was clearly justified in the treatment of mental illness and some rare, acute psychotic, manifestations of dementia. In the opinion of Professor Ibrahim, the overprescribing of antipsychotics as a first line treatment for behavioural and psychological symptoms of dementia is 'a major, systemic industry-wide issue'.*⁷³⁸

The Royal Commission suggested overuse of medications may be due in part to workload pressures and a lack of support to staff members to deliver alternatives.⁷³⁹

7.8.5 Medication administration and management/pain management

Stakeholders referred to a range of issues in relation to medication administration and management, including under and overuse of medications and the use of psychotropic medication, particularly for restraint purposes.

The ANZSGM stated in their submission 'There is evidence of both under and overuse of medications in this setting, either potentially causing harm or failing to treat the treatable'.⁷⁴⁰

Brisbane South PHN focussed on the need to de-prescribe unnecessary medications for residents where possible.⁷⁴¹

Health Professionals Say No! raised concerns that some residents of RACFs miss out on their medication due to the staffing of a facility, stating:

⁷³⁶ Submission 1208, p 4.

⁷³⁷ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 216, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁷³⁸ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 200, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁷³⁹ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, 207, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁷⁴⁰ Submission 1720, p 2.

⁷⁴¹ Submission 1212, p 4.

*We are aware of patients not receiving their required medication due to the absence of a registered nurse on the staff of residential aged care facilities at the time they are required. It is essential that there be a registered nurse at all times available in aged care facilities to receive their prescribed medication, and any emergency medication (such as pain medication) as required.*⁷⁴²

Linked closely to restrictive practices, the inappropriate use of psychotropic medicines on residents of aged care facilities was raised by a number of stakeholders. Of particular concern to the ANZSGM is the level of unnecessary use of psychotropic medicines to manage people with dementia. Its submission stated:

*One particularly worrying example is the high level of unnecessary use of psychotropic medicines (which include anti-psychotics) to manage people with dementia. Research shows that more than 80 per cent of aged care residents with dementia receive psychotropics (Hosia-Randell & Pitkälä, 2005; NPS Health News and Evidence, 2013), even though as few as 10 per cent might benefit from them (van der Spek K, Gerritsen D, Smalbrugge M, et al) and only 10 per cent of the psychotropic drug use for neuropsychiatric symptoms in patients with dementia is fully appropriate,(The PROPER I-study. Int Psychogeriatr 2016; 28: 1589-1595), while others might experience severe side effects such as stroke, falls or even premature death.*⁷⁴³

The Pharmaceutical Society of Australia similarly submitted:

*Australian studies published over recent years provide clear evidence that the high rates of antipsychotic prescribing in residential aged care facilities continue to be a significant concern. Australian evidence suggests that between 40% and 50% of residents could be receiving potentially inappropriate medications, such as sedatives and anticholinergic drugs.*⁷⁴⁴

The RANZCP also referred to inappropriate and high rates of psychotropic medication being used in RACFs rather than the preferred psychosocial interventions, submitting:

*People in Australian RACFs, similar to those in many countries, have high rates of sleep disturbance, anxiety, depression, and BPSD [behavioural and psychological symptoms of dementia] (Westbury et al., 2018). Professional guidelines advocate for non-pharmaceutical management for these conditions as the first port of call. For instance, RANZCP recommends patients with dementia and depression should receive psychosocial interventions in the first instance (RANZCP Position Statement 81) and considers the first-line approach to management of BPSD is a person-centred psychosocial, multidisciplinary treatment plan (RANZCP Professional Practice Guideline 10). However in most cases psychotropic medications (e.g. antipsychotics, antidepressants) are prescribed, and it is widely established that Australia has inappropriate and high rates of psychotropic medication being used in RACFs (Westbury et al., 2018; Brimelow et al., 2018).*⁷⁴⁵

The RANZCP referred to research by Looi et al. (2013) who argue that the overuse of psychotropic medication is a symptom of systemic problems in the provision of mental health care in RACFs. These problems include:

- *inadequate levels of poorly remunerated staff with limited mental health and behavioural management training*
- *facilities without ready access to multidisciplinary input from psychiatrists, GPs, clinical older adult psychologists and other specialist mental health workers*

⁷⁴² Submission 1265, attachment, p 1.

⁷⁴³ Submission 1720, p 2.

⁷⁴⁴ Submission 1298, p 3.

⁷⁴⁵ Submission 1207, p5.

- *activity programs that are insufficiently tailored to the specific needs of people with dementia*
- *physical design limitations that do not provide a supportive prosthetic or therapeutic environment for people with dementia.*⁷⁴⁶

According to the RANZCP, Looi et al (2013) states that these problems require broad scale interventions, such as the provision of services for the prompt assessment of people with mental illness, and changes in the design and organisational culture of RACF towards improving the mental wellbeing of residents (Looi et al., 2013).⁷⁴⁷

The Pharmaceutical Society of Australia called for pharmacists to have a greater role in the residential aged care sector, and recommended that the Queensland Government allocate funding to embed pharmacists into its public sector aged care services located within Queensland to assist in improving the health outcomes of residents.⁷⁴⁸ The reasoning for such a proposal was as follows:

The health of older people can be complicated by the presence of many chronic conditions, and the subsequent need to take multiple medications. The care and medication management of aged care residents are becoming more and more complex, as people are older and frailer when they enter aged care facilities.

*While the need to treat multiple conditions is recognised, the risk of adverse drug events increases with the number of medications prescribed. When this risk is combined with the age-related changes in how medications act, and are cleared from the body, it leads to medication-related problems being commonly reported in older people. Therefore, medication management services play a paramount role in supporting the safe and effective use of medicines for those living in residential care facilities.*⁷⁴⁹

...

Many older people have multiple chronic health conditions and this has a number of potential consequences.

- *Older people may be prescribed multiple medicines (polypharmacy), resulting in a significant increase in the potential for adverse effects and drug interactions.*
- *Many age-associated health conditions can modify the pharmacokinetic and pharmacodynamics properties of a medicine, increasing the variability in response to medicines.*
- *More than one medicine is often needed to manage each health condition. As more medicines are added to the medication regimen, the increased 'pill burden' increases the risk of poor adherence, confusion and adverse effects.*

As such, medicine use in older people can often require prescribing of unusual doses and combinations of medicines or the need to tailor for specific individual needs such as swallowing difficulties, impaired sight and hearing difficulties.

⁷⁴⁶ Submission 1207, attachment, p 5; Looi J, Byrne G, Macfarlane S, McKay R & O'Connor D (2013) Systemic approach to behavioural and psychological symptoms of dementia in residential aged care facilities. *Australia and New Zealand Journal of Psychiatry* 48(2): 112/115.

⁷⁴⁷ Submission 1207, attachment, p 5; Looi J, Byrne G, Macfarlane S, McKay R & O'Connor D (2013) Systemic approach to behavioural and psychological symptoms of dementia in residential aged care facilities. *Australia and New Zealand Journal of Psychiatry* 48(2): 112/115.

⁷⁴⁸ Submission 1298, p 3, 5.

⁷⁴⁹ Submission 1298, p 2.

*The elderly are also at increased risk of adverse or suboptimal effects of medications, not only as a result of their complex medication regimens and disease states, but also due to frailty and functional decline compared to younger populations. The frequently reported occurrence of medication misadventure in residential aged care facilities has many causative factors including general poor health status, high use of medicines, polypharmacy and the extensive over prescribing of sedatives and psychotropic medicines among this population.*⁷⁵⁰

The Royal Commission also heard evidence of over-prescription of medication, specifically psychotropic medication. It reported:

...research involving 150 residential aged care facilities found that 61% of residents were regularly taking psychotropic agents, with 41% prescribed antidepressants, 22% prescribed antipsychotics, and 22% prescribed benzodiazepines.

*...an Australian Department of Health expert clinical advisory panel estimated that psychotropic medication is only clearly justified in about 10% of cases in which they are prescribed in residential aged care.*⁷⁵¹

7.8.6 Access to palliative care in residential aged care

Stakeholders raised concerns that RACFs are not meeting the palliative care needs of their residents and that there are inconsistent approaches to provision of Queensland Government funded palliative care services into residential aged care facilities.⁷⁵² Reasons given for this included insufficient resources and staff being allocated to palliative care needs, as well as insufficient training of staff.

The Uniting Church in Australia Queensland Synod, amongst other stakeholders, raised the issue that aged care funding does not support people's palliative care needs, and argued that 'the State needs to address access for this client group'.⁷⁵³

PCQ submitted that palliative care is not seen as, or supported systematically to be, core business within aged care. PCQ states this is despite the Quality of Care Principles 2014 (made under section 96 of the Aged Care Act) providing that approved residential aged care providers are responsible for providing access to a qualified practitioner from a palliative care team and also provide for the establishment of a palliative care program, including monitoring and managing any side effects for any resident that needs it.⁷⁵⁴

To emphasise this point, PCQ stated that palliative care is not mentioned in the new Aged Care Quality Standards, and only makes reference to end-of-life care twice, which 'represents a specific time frame and narrows the focus to the dying phase allowing opportunities for earlier support to be overlooked, particularly within aged care'.⁷⁵⁵ PCQ submitted:

This lack of prominence of palliative care within aged care at all levels including policy, systems, education and training, is impacting on individuals, families, aged care staff and the broader community's experiences and perceptions of aged care (particularly residential aged care), death and dying, as well as the rates of avoidable or unnecessary hospital admissions, increased costs across systems and sectors, and grief and bereavement support.

⁷⁵⁰ Submission 1298, p 3.

⁷⁵¹ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 7, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁷⁵² Submission 1245, attachment, p 3.

⁷⁵³ Submission 1268, p 29.

⁷⁵⁴ Quality of Care Principles 2014, Part 3, <https://www.legislation.gov.au/Details/C2019C00199>.

⁷⁵⁵ Submission 1891, p 41.

*Too often, people are transferred back and forth between hospitals and aged care facilities, as aged care facilities lack palliative care expertise and qualified staff to administer pain relief.*⁷⁵⁶

PCQ called for increased funding to support quality palliative care in the community and residential aged care.⁷⁵⁷ PCQ submitted that 'The barriers around funding (Federal v. State) need to be torn down to facilitate primary and secondary/tertiary care working together for the benefit of older people'.⁷⁵⁸

AASW Qld Branch advised that RACFs will relocate patients to hospital when they cannot manage complex care needs, including end-of-life care. The AASW states:

*This can be very disruptive for people and, depending on the circumstances, can impact negatively on the relationships between individuals, families, hospitals and aged care providers. Ideally, a person should be supported to receive care and die in a location of their choice, with familiar people and surroundings.*⁷⁵⁹

The Cancer Council Qld wrote of the calls received via the PalAssist support line from people needing support with nursing homes as they don't feel their family member is being cared for appropriately. These callers report that some nursing staff are not able to identify palliative care phases nor are they adept at putting palliative care plans in place.⁷⁶⁰ Cancer Council Qld also advised:

*PalAssist clients inform us that palliative care delivery in residential aged care facilities (RACFs) can be lacking, with differing options for support and education for RACF staff, especially in rural and remote areas...almost a quarter of callers (23%) to our PalAssist service in 2018 were general practitioners and health professionals, and another 13.3% were carers. These figures suggest that additional support is needed to support professionals working in residential aged care facilities. Queensland Health should extend educational opportunities and training resources in end-of-life decision making to all caring staff in residential aged care facilities, as part of the implementation of the Statewide strategy for end-of-life care 2015.*⁷⁶¹

The QLS stated that 'Significantly increased attention, upskilling and resources are required to facilitate palliative care provisions in aged care', submitting

*Only 2% of Australians living in aged care were referred to palliative care specialist teams, which is in considerable contrast to the 71% of aged care 'exits' attributable to death of the resident. It is reasonable to presume that a sizeable number of these deaths could have been supported with palliative care, if adequate services were available.*⁷⁶²

Ms Julie Long provided the following example to support her belief that aged care facilities do not have the resources to adequately care for residents requiring palliative care staff and that specialised palliative care services should operate in aged care facilities because palliative care is a specialised service and requires specially trained staff:

Two years ago I watched as my elderly uncle suffered a slow and painful death. He had cancer. As his health deteriorated he was admitted to the Palliative Care Unit at Redcliffe hospital. Unfortunately as his death wasn't imminent, he was unable to stay in the Palliative Care Unit and we had to place him in a residential aged care facility at Lawnton. He passed away just 13 days after moving into the facility.

⁷⁵⁶ Submission 1891, p 41.

⁷⁵⁷ Submission 1891, p 45.

⁷⁵⁸ Submission 1891, p 50.

⁷⁵⁹ Submission 1288, p 17.

⁷⁶⁰ Submission 1303, attachment, p 3.

⁷⁶¹ Submission 1303, attachment, p 4.

⁷⁶² Submission 1201, p 6.

As a family we found the whole situation extremely distressing. Not only was it distressing watching my uncle suffer but we were extremely disappointed when we were told he could no longer stay in the Palliative Care Unit at Redcliffe Hospital and that we would have to find him accommodation in an aged care facility.

I believe the end of life care he received both in the Palliative Care Unit at Redcliffe and at Pinewoods Lawnton was suboptimal. We believe having to relocate a dying man in the final days of his life was cruel and unnecessary. Despite us being assured that staff were trained in palliative care at Pinewoods, staff insisted on serving my uncle a meal when just the smell of food made him sick. He was dying. He didn't have an appetite. A spoonful of ice-cream or yoghurt was all that he could cope with but they continued to serve him a vitamised mix of meat and vegetables that only exacerbated his nausea. It would seem staff did not understand the dying process but were only concerned with meeting policies and procedures. People are individuals and all require individual specialised care and attention. Blue Care claims to provide person-centred care. This unfortunately was not what we or my uncle experienced in the final days of his life.

During the final 24 hours of his life my uncle's health deteriorated rapidly. Staff did administer pain relief at our request but we were concerned that he would fall out of bed as he was getting quite agitated during the evening. Staff refused to put the rails up on his bed as that was against Blue Care policy, so my sister pushed a recliner chair up against one side of his bed and I sat in a chair on the other side of his bed. My sister stayed with him throughout the night keeping watch as he tried to pull out his oxygen tubes and go to the toilet. Staff would check on him occasionally or when we felt he needed more pain relief.⁷⁶³

Ms Gwenneth Swanson, a resident of a RACF, advised she believes there is an insufficient staff to resident ratio and that staff do not have sufficient training in end-of-life and specialised palliative care. Ms Swanson provided the following example of an instance at her RACF to the committee:

For example, I have personally witnessed a fellow resident die a painful and undignified death. It was in the early hours one morning when I could hear him struggling for breath, he was extremely agitated and distressed. He was alone in his room and it was clear that he was dying. I went to the nurses station and approached staff explaining that the resident was dying and needed care and attention. Staff attended to him at my request and the poor fellow passed away later that morning. However, I believe the level of end-of-life care provided in this case did not meet the standards of Residential Aged Care.⁷⁶⁴

Dr David McFarlane also provided an example of the treatment of his mother in an RACF:

After my mother fall / [sic] was dropped (requiring admission to a private hospital) I was told that there was no fracture. A CT performed at my request revealed fractured vertebrae and ribs. She had to be lifted by hoist for the last few months of her life, often crying in pain. There was supposed to be engagement with the palliative care team from a major southside hospital, but the only visit they made was at my insistence. I had to ask for medications to dry secretions and relieve distress – something no son should be asked to do. I saw no use of modern analgesics. Eventually regular staff were assigned to my mother where shifts permitted, and those staff are to be commended for their efforts. Dying patients nursed in standard rooms with standard staff ratios. I had to identify my mother's naked body was identified for the funeral directors -no wrist band. These facilities are not hospitals, but places where increasing numbers of people live. There needs to be a balance between dignity, affordability, minimum standards and compassion. Currently this is patently lacking.⁷⁶⁵

⁷⁶³ Submission 1937, pp 1-2.

⁷⁶⁴ Submission 1950, p 1.

⁷⁶⁵ Submission E1634.

Health Professional Say No! submitted that they are aware of aged care facilities who do not allow palliative care teams onto their premises to see patients, and/or doctors who do not prescribe the treatments recommended by the palliative care team, stating ‘all of these practices result in inferior care for patients/clients’.⁷⁶⁶

Catholic Health Australia addressed the benefits of providing specialist palliative care access to residents at their RACFs rather than in hospital:

*Of particular relevance to this inquiry, is timely access to specialist PC services. However, access to specialist PC services provided by PC specialists and specialist nurse practitioners varies across regions and jurisdictions, and is often dependent on health priorities determined at the local level. Notwithstanding this, there are examples where it has been demonstrated that in-reach PC services reduce health system costs and result in better outcomes for people. For example, a program operating in the ACT that provides aged care residents access to specialist care nurse practitioners, education and support for aged care staff and access to equipment has been demonstrated to not only improve the palliative care experience of residents but also to reduce hospital costs.*⁷⁶⁷

AMA Queensland recommended that more attention be placed on the interface between palliative care and aged care, with GPs and allied health professionals being better supported to provide palliative care in RACFs:

Today many patients receiving palliative care, who are too ill to live in their own homes, reside in residential aged care facilities (RACFs). Feedback from AMA Queensland’s General Practitioner members indicates the medical care offered to patients who move into RACFs is fractured and difficult to access.

When a patient moves into an RACF they lose a large part of their independence, including the opportunity to visit their own GP. GPs report that they find it extremely difficult to treat their patients in RACFs due to limited organisational support at some RACFs and poor financial incentives. Many GPs are forced to relinquish giving care to these patients. Other GPs provide extra, unpaid, work to patients and their families by writing prescriptions out of hours and providing bereavement support.

*This is not a sustainable model of care. GPs need to be supported to provide care to patients in RACFs. The Queensland Government should lobby the Commonwealth Government for increased Medicare payments for GPs and other allied health groups to provide palliative treatment to patients in RACFs. Increased medical treatment in RACFs is an efficient way of treating patients and will relieve pressure on acute treatment beds in hospitals.*⁷⁶⁸

7.8.7 Other issues with residential aged care facilities

The following is a summary of other issues that were raised by stakeholders during the inquiry.

7.8.7.1 Dignity of risk and loss of autonomy

The Queensland branch of the AASW raised the issue of the dignity of risk, submitting:

Dignity of risk is another issue in relation to working with clients and residents with capacity concerns. Staff are not always trained and can lack awareness in understanding how to work appropriately with someone with questionable capacity. When this happens, they will often communicate with a person’s nominated Attorney and bypass the older person who is still able to understand and communicate their decisions. Further work is required to develop standards

⁷⁶⁶ Submission 1265, attachment, p 1.

⁷⁶⁷ Submission 1249, attachment, p 2.

⁷⁶⁸ Submission 1233, p 6.

*for working with the older person at all times, as well as guidelines on how to do this effectively when a person has questionable capacity.*⁷⁶⁹

Ms Gillian Nicholl referred to her experience of an RACF:

*Everything was done at the convenience of the institution, the patients did not get to choose when any of their activities of daily living would happen. Their lives reduced to 2 rooms if they were lucky or it was 1 room and down to the dinning [sic] room for meals even if they did not want to eat.*⁷⁷⁰

Ms Brenda Blee provided the following example of choice and independent decision-making being taken away from residents:

*The nursing home wanted my mother to wear joggers to go on their walks not the shoes she preferred as they considered joggers safer. Mum didn't want to wear the joggers. The Nursing Director at the time said she'll wear them, she'll have no choice she's not far from not knowing. I removed the joggers, my mother would choose what she wore. I arrived one day not long after this to find everyone, both male and female, in high care dementia had the same haircut. Short back and sides. My mother had never had short hair and hated it. After my complaint, Mum never had short hair again and the nurse left not long after. No person in aged care should be denied the right to choose...Lifestyle should be a choice for all of life. I do not want the lifestyle my father had for months, my mother for years as they did not want it. They had no choice, I hope to have a choice.*⁷⁷¹

Ms Rhonda Nilsson provided another example:

*When someone enters an aged care facility, this is their home but many times mum was made to feel like a burden, a bother, a naughty child, e.g. she was always told that her room was too messy (she had a lot of knick-knacks, a messy writing desk but nothing that would cause a WH&S concern) and she was being constantly reminded of this. When I looked at the other 'compliant' residents rooms, they looked like a hotel room. In the dining room, mum kept a placemat on her table with her favourite sauces etc. After a while, we were told this was not allowed as it was a health hazard. Hello! Mum had it cleaned each week and it 'personalised' her table. She was most upset when it was removed. This is not a hospital!*⁷⁷²

Evidence provided to the Royal Commission also addressed the issue of consumerism/lack of person-centric systems and care. The Royal Commission stated in its interim report:

*We have heard countless stories about how much people grieve for all they have lost when they arrive in residential care. They become 'just a resident', just another body to be washed, fed and mobilised, their value defined by the amount of funding they bring with them. They become infantilised, lose autonomy, and are prevented from making decisions or doing physical things that were routine when they lived at home, on the grounds that they 'could hurt themselves'. They lose their basic rights to take risks, to choose what to do in their day, to live a life as close as possible to their previous home and community. There is no joy in this.*⁷⁷³

...

⁷⁶⁹ Submission 1288, p 13.

⁷⁷⁰ Submission E738.

⁷⁷¹ Submission 1922, p 2.

⁷⁷² Submission 1083, pp 3-4.

⁷⁷³ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 4, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

*It is shameful that such a list can be produced in 21st century Australia. At the heart of these problems lies the fundamental fact that our aged care system essentially depersonalises older people.*⁷⁷⁴

The Royal Commission also commented on the loss of autonomy and individuality in its Interim Report:

*People do not usually enter residential aged care willingly. They often do so with great trepidation. They fear loss of autonomy, of individuality, of control over their own lives. They fear ceasing to be a person with distinct needs and preferences, with an emotional and intellectual life and freedom to do what they want, when they want to do it.*⁷⁷⁵

The QLS addressed the likely change in approach that will be required to service the baby boomer generation, submitting:

*...a cultural evolution of community attitudes towards bodily autonomy, respect for mental capacity and notions of supported decision-making, and doctor-patient collaboration in health care decision-making may also have an impact. Previous generations have been more compliant with medical opinion and were less likely to complain or challenge authority. The next generation to move into aged care - the 'Baby Boomers' - will be more demanding. Care services will be driven by a 'rights focussed' cohort, unwilling to be passive and overlooked.*⁷⁷⁶

7.8.7.2 Social needs/diversional therapy/lifestyle

A number of submitters also raised the importance of providing activities to increase social connectedness as well as physical and mental engagement.

Queensland PHNs raised concerns that residents of RACFs have minimal access to the outdoors and low rates of visitors if any for many residents, stating:

*Social isolation is increasingly recognised as a major contributor to poor psychological and physical health.*⁷⁷⁷ *Social Isolation is recognised as a major factor in psychological and physical health but there is insufficient investment into social connection as a preventative measure.*⁷⁷⁸

The Public Health Association of Australia also identified social isolation as a health issue, submitting:

*Social connections are being increasingly understood as a determinant of living longer (Pinker 2007), and policies that aim to support healthy aging and improve aged care should also aim to create opportunities for community connectedness. For older people social isolation impairs health (Steptoe, Shankar, Demakakos, Wardle 2013).*⁷⁷⁹

The AASW Qld Branch raised particular concerns for people living with dementia and cognitive decline, advising these people often experience significant confusion when moving into residential aged care as they are removed from their familiar environment. Meanwhile, older people in community settings face isolation as their functional abilities decrease and they become less active in their communities.⁷⁸⁰

⁷⁷⁴ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 6, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁷⁷⁵ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 4, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁷⁷⁶ Submission 1201, p 6.

⁷⁷⁷ Submission 1301, p 3.

⁷⁷⁸ Submission 1301, p 7.

⁷⁷⁹ Submission 1239, p 5.

⁷⁸⁰ Submission 1288, p 7.

The AASW Qld Branch submitted that programs and activities focused on meeting the individual needs of the client to increase social connectedness need to be expanded, suggesting:

*The Community Visitor's Scheme provides volunteers to conduct one-on-one social support to residents and clients in the community, however, some older people can find it difficult to engage with this service due to limited resources or reluctance to access the scheme. People are often concerned about the unknown factors of connecting with a stranger who is not associated with their home, facility or care provider. Unfortunately, group activities such as day respite, joint activities and outings in residential aged care do not always meet individual needs either. This is particularly true for people from special needs groups, and those with mobility restrictions or other functional limitations who cannot easily access such activities. Affordable transport in the community and residential aged care to access external activities is limited, sometimes with only one option available which is not always suitable.*⁷⁸¹

Submitters also argued for better integration of programs that support an older persons mental and physical engagement. Dr David McFarlane made the following comments on his experience with his parents:

*There is minimal effort to keep patients engaged at a level consistent with physical and intellectual capacity to improve quality and maintain quality of life and reduce burden of care. Easiest to wheel patients out into lounge and leave watching TV. Activities often banal. Minimal physiotherapy / speech pathologist / occupational engagement or feedback. Often had to initiate and pay for additional care. Visiting dentist charges 4x that of local dentist with no health fund rebates...No excursions. No outdoor activities.*⁷⁸²

The Upper Mt Gravatt Wishart Catholic Parish similarly submitted that the activities provided to residents should uphold the dignity of the resident, stating 'At present, the skill level required for most activities would barely challenge a pre-schooler'.⁷⁸³

Brisbane South PHN argued that the 'value of diversional therapy / lifestyle / activity based programs and workforce training in these areas needs to be more formalised, elevated to a higher qualification and adequately funded'.⁷⁸⁴

Dr Carol Portman recommended extending city and state programmes that already exist in the community to support mental and physical engagement (yoga, dance, craft, computers, reading) to include aged care and support facilities. Dr Portman suggested that extending existing programs would help with some of the management and oversight responsibility and budget.⁷⁸⁵

Mr Keith Rickart advised that activities specifically designed for residents with dementia needed to be incorporated in regular daily routines in age care facilities.⁷⁸⁶

7.8.7.3 Design of facilities

The inadequate design of facilities for the needs of current residents was also raised by some stakeholders. For example, LCAQD advised that it has numerous service locations, which represent a variety of physical infrastructure configurations:

Some of these built-form configurations were developed in times past to suit now superseded modes of care - such as "low care" in the 1970s to 1990s. These are not the best configurations

⁷⁸¹ Submission 1288, p 7.

⁷⁸² Submission E1634.

⁷⁸³ Submission 1309, p 2.

⁷⁸⁴ Submission 1212, p 4.

⁷⁸⁵ Submission 1836, p 2.

⁷⁸⁶ Submission E911.

for the quality care of residents with the highest care needs today. It is a challenge for a provider like Lutheran Services to maintain or modify such infrastructure in line with the changing profile and demands of contemporary aged care.

*Contemporary thinking suggests providers of future residential services should offer smaller pods or clusters of bedrooms with common areas, thus creating a stronger, home-like experience. We have demonstrated the benefits of such a model with one of our newer developments. Northridge Salem at Toowoomba has created a smaller, more intimate care environment, resulting in fewer complaints or concerns of care.*⁷⁸⁷

Queensland PHNs commented that much of the current bed stock will require replacement over the next 10 years, and stated that ‘While there are new contemporary facilities being constructed, there are also examples of new constructions of old models of care’.⁷⁸⁸

Brisbane South PHN commented that because residents of aged care are not one homogenous group consideration should be given to the differing care needs of each individual, stating ‘This requires different, and potentially multiple, models of care, which should be inclusive of clinical care, social support and the impact of the design of the built environment’.⁷⁸⁹

SVHA submitted that RACFs need updating and/or better purpose built facilities need to be constructed so these facilities are able to deliver the appropriate care to elderly residents with special needs that need to be accommodated within a residential service.⁷⁹⁰

Dr David McFarlane described the issues with the RACF that his mother lived in:

*Brand new, but poorly designed, with sharp and unprotected corners, no vinyl bumpers on walls (an excuse to charge capital refurbishment fees on ‘exit’), inaccessible fittings, shelves and switches. I understand the architects were PDT – who have previously designed hospitals. Fittings and appearance worn very quickly. Multiple leaks and administration unresponsive to replace the very cheap fans and room safes even if faulty. Cannot install better quality even if offer to pay. Television screens for example are 26” 4m away – for people with poor vision. Inadequate areas for relatives and residents to congregate. Only one access path for wheelchair/walker patients. When lift failed – isolated for 3-4 hours.*⁷⁹¹

7.9 Issues with residential respite care

Concerns were also raised about access to respite care within RACFs. Queensland PHNs stated that there are inadequate systems to support respite care for older people who need to move in and out of respite to give their family or carer a break, arguing that the system is set up for permanent residents:

*Older people who do get into respite within residential aged care often struggle to get out again because of funding constraints limiting the opportunity for only short term episodic care provision. The system is incentivised to support older people in residential aged care as a permanent occupant. If more people were able to be accommodated for interim periods for rehabilitation (e.g.: post hospitalisation as with Transition Care Program) they may be reabled to return home.*⁷⁹²

⁷⁸⁷ Submission 1277, p 6.

⁷⁸⁸ Submission 1301, p 6.

⁷⁸⁹ Submission 1212, p 6.

⁷⁹⁰ Submission 1280, p 11.

⁷⁹¹ Submission E1634.

⁷⁹² Submission 1301, p 3.

Ms Linda Mungomery submitted that respite care is poorly done and is difficult to access in quality settings, particularly for those with dementia.⁷⁹³ Ms Mungomery provided the following example:

*There seemed to be little awareness of the limitations of Dad's dementia despite us providing detailed history and support notes. He would be restrained/harnessed in his wheel chair and left in a room alone, with a buzzer nearby that he made no association with or could ever use and a jug of water that he had no idea what to do with and was rarely offered water. His mobilisation was limited to hoists, he went into care [one of his carers was undergoing chemotherapy so we had dad in respite for 3 weeks] being able to walk and weightbear enough to transfer with one assistant. He came home unable to mobilise, weaker and had also contracted scabies. It was incredibly distressing for dad and us.*⁷⁹⁴

Committee Comment

Despite the Australian Government's significant expenditure, under-resourcing remains a problem for the residential aged care program. Changes the Australian Government made in 2016 and 2017 effectively cut providers' revenue whilst their operating costs, particularly staff costs, continued to increase. Faced by difficult financial conditions, it appears that some operators have shifted their focus from quality of care to cost of care out of necessity, resulting in poorer care outcomes for residents.

The problem of increasing waiting times to access residential care was raised often by stakeholders during the committee's inquiry, even with a rise in vacancies. There is a particular shortage of places in residential aged care facilities in rural and regional areas. This leads to extended delays in the placement of residents in these areas, limits the choice for residents and, in many cases, forces residents to accept places in locations away from their homes and loved ones. The current wait times impose enormous pressures on the elderly, their families and carers.

The lack of residential care places also results in acute beds in hospitals being used to house elderly patients waiting to be placed in residential care. These circumstances place increased pressure on the Queensland public health system and contribute to 'bed blockage' or 'access block'.

Stakeholders also raised concerns about the high entry and daily charges levied by residential care providers, the level of information provided by providers to residents about the charges levied, the lack of transparency in how residential aged care facilities spend funds they receive from government and residents.

Demand for short-term planned or emergency residential care, known as respite care, is rapidly increasing – more than three times as fast as the rising demand for residential care. Demand for high level respite care is particularly strong. Respite care is offered through residential aged care facilities, though respite residents do not make any means-tested accommodation or care contributions.

⁷⁹³ Submission 1370, p 1.

⁷⁹⁴ Submission 1370, p 2.

Care provided

The Australian Government has established a charter of Aged Care Rights, Aged Care Quality Standards, a Mandatory Quality Indicator Program and a Serious Incident Response Scheme to guide the delivery of aged care by providers. Further controls on the use of restraint on residents exist under the Quality of Care Principles made under the *Aged Care Act 1997* (Cwlth). The committee reported on excessive use of restraint in its report on the closure of the Earle Haven residential aged care facility. The Australian Government's controls on the use of restraint in aged care were strengthened in late November 2019. They now refer to state and territory legislation for prescribers' responsibilities regarding informed consent. The committee welcomes this tightening of controls. It remains concerned however that restraint is being overused on residents as a substitute for adequate staffing levels and supervision by staff in facilities.

Staffing

A common theme in submissions and other evidence about aged care is that there are insufficient staff and too few registered nurses in residential aged care facilities, and that this impacts on the time allocated to caring duties in residential aged care facilities. This leads to compromises in the quality of care being provided. Understaffing issues are more critical at night times and on weekends. The committee heard that inconsistencies in pain management and missed medications, increased falls, poor record management, poor timeliness for toileting of residents, the overuse of incontinence pads, increased pressure injuries and skin tears, the overuse of restraint on residents, reduced structured activities for residents, and rushed meals are examples of missed care issues that are symptomatic of the lack of staffing.

The committee heard that care for frail residents and those with dementia is particularly affected by staffing shortfalls. The committee also heard that the amount of care provided to residents in Australian facilities compares poorly with care provided in facilities in the United States of America and against recommended care benchmarks of 4.3 hours of care per day for residents.

Further issues were raised about the qualifications and experience of staff in residential aged care, particularly the lack of experienced registered nurses in facilities. Concerns about the qualifications and training of staff raised issues with the care of residents with dementia. The lack of clinical care staff was also linked to increased numbers of residents being sent from residential care facilities to hospitals for treatment of relatively minor medical conditions.

The short-staffing of residential aged care facilities also impacts on the welfare of staff.

The committee supports the introduction of the transparency measures legislated in the *Health Transparency Act 2019* (Qld) to establish minimum standards for staffing and care for public residential aged care facilities and to encourage the disclosure of staffing levels in private residential aged care facilities in Queensland.

The committee also notes the Royal Commission Interim Report calls for more transparency across the aged care sector.

Access to palliative care in residential aged care facilities

Palliative care is not acknowledged as core business within residential aged care facilities. Funding responsibility for palliative care in facilities is also unclear. Staff providing palliative care in residential facilities require additional qualifications, training and skills. Yet the committee heard of instances where the care of residents at the end of their life has fallen largely to personal carers. The committee endorses the view of the Queensland Law Society that 'Significantly increased attention, upskilling and resources are required to facilitate palliative care provision in aged care'. This should be a joint responsibility of the Australian and Queensland Governments.

Further discussion of this issue and relevant recommendations are made at section 15.2.5 of this report.

Other issues in residential aged care facilities

Activities to increase social connectedness as well as physical and mental engagement are a critically important component of aged care for maintaining dignity and quality of life, particularly for residents suffering dementia and cognitive decline. These programs need to be properly integrated into aged care. For this to be achieved, these activities need to be funded by the Australian Government.

Recommendation 17 Controls on physical and chemical restraints

The committee recommends that the Australian Government continues to examine and reform practices regarding physical and chemical restraints to discourage providers from using restraints as substitutes for appropriate levels of care and supervision.

Recommendation 18 Better nutrition

The committee recommends that the Australian Government require that meals provided in residential aged care facilities meets the nutritional guidelines for older people provided by the National Health and Medical Research Council's *Australian Dietary Guidelines*.

Recommendation 19 Funding for activities to increase residents' social connectedness

The committee recommends that the Australian Government consider providing funding for activities to increase residents' social connectedness as well as physical and mental engagement in residential aged care facilities.

Recommendation 20 Disclosure of staff to resident ratios at residential aged care facilities

The committee recommends that the Australian Government require providers to display in a public common area at each residential aged care facility the staff to resident ratios at that facility across each shift, for the information of residents, prospective residents and their representatives.

Recommendation 21 Publication of staff to resident ratios on the My Aged Care website

The committee recommends that the Australian Government require that information about residential aged care facilities that is published in the Schedule to the My Aged Care website includes staff to resident ratios at each of those facilities.

Recommendation 22 Advance Health Directives in residential aged care facilities

The committee recommends that the Australian Government require residential aged care facilities to provide information and encourage residents to complete an Advance Health Directive as soon as possible after entry to the facility. This information should be readily available for relevant health care workers.

8 Other care programs

8.1 Flexible care

8.1.1 Overview

Flexible care allows for a different care approach than that provided through mainstream residential aged care and home care.⁷⁹⁵

There are five flexible care programs:

- Transition Care
- Short-Term Restorative Care
- Multi-Purpose Services
- Innovative Care
- National Aboriginal and Torres Strait Islander Flexible Aged Care.⁷⁹⁶

As at 30 June 2019, there were 9,644 operational flexible care places, an increase from 9,073 operational flexible care places in the previous year. Funding similarly increased, with \$516.0 million in Australian Government funding across these programs. In 2017-18, Australian Government funding totalled \$490.9 million.⁷⁹⁷

8.1.2 Transition Care Programme

The Transition Care Programme, established in 2005-6 provides short-term care for older people following discharge from hospital. The program aims to help senior Australians who would otherwise be eligible for residential care to optimise their functional capacity and improve their levels of independence by providing time-limited, goal-oriented and therapy-focused packages of services which include low intensity therapy, social work, and nursing support or personal care.⁷⁹⁸

People may receive transition care for up to 12 weeks (with a possible extension of another six weeks) in either a community (home) or residential care setting. To be assessed as eligible for transition care support, a person must be in hospital at the time of the assessment. The assessment is undertaken by an ACAT.⁷⁹⁹

⁷⁹⁵ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 13; Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 2, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁷⁹⁶ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 13.

⁷⁹⁷ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 13; Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 2, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf; Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 54.

⁷⁹⁸ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 13; Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 36, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁷⁹⁹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 13.

In 2018–19, the average length of stay for completed episodes of transition care was 53.2 days. The occupancy rate for transition care throughout 2018–19 was 88.4 per cent.⁸⁰⁰

The Australian Government has agreements in place with each of the state and territory governments, as the approved providers of transition care, to manage the program in their respective jurisdictions. Most state and territory governments then subcontract the provision of these services.⁸⁰¹

As at 30 June 2019, there were 4,060 transition care places across Australia, with 733 in Queensland.⁸⁰² During 2018–19, a total of 24,432 people received transition care, with 4,467 receiving transition care in Queensland.⁸⁰³

As a jointly-funded initiative, both the Australian Government and state and territory governments contribute to the cost of the program. In 2018–19, Australian Government funding for the Transition Care Programme was \$266.7 million, a slight decrease from \$267.6 million provided in 2017–18.⁸⁰⁴ Australian Government funding is provided in the form of a flexible-care subsidy, payable to the provider for each person who receives services.⁸⁰⁵

8.1.2.1 *Issues with the Transition Care Programme:*

A number of submitters raised issues with the Transition Care Programme, including eligible patients not being offered access to the program and there not being enough places for those eligible.

The QLS noted that the ambition of transition care is to reinstate the patient to how and where they were, prior to a hospital admission, and that access to transition care is reliant on the hospital discharge plan providing and organising the necessary requirements for a particular patient. The QLS stated:

*We understand that it is often overlooked and discharge without care forfeits this opportunity. It is reportedly of a good quality and quantity of additional short-term (12 weeks) care. As mentioned, it is not always made available to eligible patients, based on perceptions of long term viability and other discernments by the hospital staff.*⁸⁰⁶

The QLS also referred to anecdotal evidence that patients are held in hospitals because they refuse to agree to an aged care placement, instead preferring to return home. A hospital may instigate tribunal proceedings to seek a substitute decision maker for accommodation matters. The QLS advised that often these patients report they were not offered transition care or an opportunity to trial returning home with services to assist.⁸⁰⁷

⁸⁰⁰ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 55, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁸⁰¹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 13.

⁸⁰² Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 14; Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 55, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2018-19-ROACA.pdf.

⁸⁰³ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 56, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁸⁰⁴ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 14.

⁸⁰⁵ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 37, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf; Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 56, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2018-19-ROACA.pdf.

⁸⁰⁶ Submission 1201, p 5.

⁸⁰⁷ Submission 1201, pp 7–8.

Reverend Stefan Slucki referred to older people not receiving the care they were entitled to, and subsequently being kept at the RACF on a permanent basis. He stated:

In my observation, the transition-care system works erratically.

Those who can advocate for themselves or have assertive advocates do okay but those suffering some level of dementia are neglected and do not seem to receive the follow-up care which might enable them to return home after a short period of rehab. Several people who claimed they were only to be at the nursing home at which I worked ended up being permanent residents, receiving little if no follow-up physio having left hospital.

*Perhaps this was a deliberate decision made for very good reason and simply not communicated to them, honestly—which is deceitful if that’s what happened, as I slowly saw frustration turn to hopelessness in their eyes.*⁸⁰⁸

Ms Erika Gerdson advised that there are not enough beds available for the programme, stating ‘During Alex’s time in the Residential Transition Care Program, they were very keen to discharge him as soon as it looked like the home modifications were completed’.

Ms Gerdson also advised that people with higher/complex levels of needs are not well provided for, telling the committee:

*Alex had a double-whammy of disabilities after his stroke – completely blind and paralysed down one side. During his rehabilitation he felt quite miserable an [sic] alone it seemed as if the staff were not used to having a patient requiring his level of care/support.*⁸⁰⁹

Ms Bernadette Systa also gave an example of her mother-in-law missing out on transition care because the rules were not properly explained to her family:

Before her husband passed away, my mother-in-law was approved for 12 weeks transition care at Redlands residential / transition care service. During her stay at the service, she was transferred to Redland hospital with high blood sugar levels. While at the hospital - she spent more than 2 days in ED before being transferred to the ward. This in itself is very disappointing, considering what she and our family has had to endure over the last couple of weeks.

Shortly after her admission to hospital, transition care called my husband and told [him] to collect her stuff because she had lost her place. This was quite distressing as she had been approved for 12 weeks transition care, therefore we thought we had 12 weeks to find appropriate residential care for her.

We were never advised that she would lose her spot in transition care if she was away longer than 24 hours. Surely this basic information can be communicated to families, so they are prepared for this outcome, should it ever eventuate?

...

*Communication between clinical services and families can be improved significantly - so there are no nasty surprises for families already experiencing grief.*⁸¹⁰

8.1.3 Short-Term Restorative Care Programme

The Short-Term Restorative Care (STRC) Programme provides early intervention care that aims to optimise the functioning and independence of older Australians, and to reverse and/or slow functional decline.⁸¹¹

⁸⁰⁸ Submission 1680, p 2.

⁸⁰⁹ Submission 1642, pp 5-6.

⁸¹⁰ Submission 1445, pp 1-2.

⁸¹¹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 14.

Consumers can receive a time-limited (up to 56 days), goal-oriented, multi-disciplinary and co-ordinated package of services and supports such as physiotherapy, social work, nursing support, personal care and the provision of assistive technologies, to enable senior Australians to regain independence and autonomy rather than entering long term care prematurely. Services may be delivered in a home care setting, a residential aged care setting, or a combination of both.⁸¹²

As at 30 June 2019, there were 82 operational STRC services being delivered by 53 approved providers, with 191 places available in Queensland.⁸¹³ During 2018–19, a total of 2,543 people received short term restorative care, with 610 people receiving care in Queensland.⁸¹⁴

In 2018-19, the Australian Government contributed \$26.7 million for STRC services in the form of a flexible care subsidy (up from \$16.7 million in 2017-18). Additionally, providers are able to charge recipients a daily care fee for the services provided under this program. The maximum basic daily rate is an amount equivalent to:

- 85 per cent of the age pension for care delivered in a residential setting
- 17.5 per cent of the age pension for care delivered in a home or community setting.⁸¹⁵

8.1.4 Multi-purpose Services Program

The Multi-purpose Services Program enables older people living in regional, rural and remote areas to receive the aged care services they need in their own community. The program allows services to exist in regions that could not viably support stand-alone hospitals or residential aged care services.⁸¹⁶ Assessment for this program is based on clinical need meaning an assessment by an ACAT is not required.⁸¹⁷

The program is a jointly funded Australian Government and state and territory government initiative. Through flexible and integrated service delivery, the program provides access to a mix of aged care, health and community services tailored to meet local community needs.⁸¹⁸ It can be provided in a residential, home or community setting.⁸¹⁹

As at 30 June 2019, there were 179 operational Multi-purpose Services, with a total of 3,646 flexible care places. There was continued growth in Australian Government expenditure for the Multi-purpose Services, from \$168.8 million in 2017–18 to \$177.3 million in 2018–19.⁸²⁰

⁸¹² Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 14.

⁸¹³ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 57, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2018-19-ROACA.pdf.

⁸¹⁴ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 57, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2018-19-ROACA.pdf.

⁸¹⁵ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 39, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf; Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 58, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2018-19-ROACA.pdf.

⁸¹⁶ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 14.

⁸¹⁷ Royal Commission into Aged Care Quality and Safety, *Navigating the maze: an overview of Australia's current aged care system*, Background Paper 1, February 2019, <https://agedcare.royalcommission.gov.au/publications/Documents/background-paper-1.pdf>.

⁸¹⁸ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 14.

⁸¹⁹ Queensland Health, correspondence dated 23 January 2019, p 5.

⁸²⁰ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 59, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2018-19-ROACA.pdf.

Multi-purpose Services are generally operated by state or territory governments or authorities. The majority of services are co-located with a hospital or health service.⁸²¹

Table 16: Number of operational Queensland Multi-purpose Services and places, at 30 June 2018

State/Territory	Multi-Purpose Services with operational places	Operational high care residential care places	Operational low care residential care places	Operational home care places	Total operational places
Queensland	36	332	118	141	591
Australia	179	2,501	675	470	3,646

Source: Australian Government, Department of Health, 2018-19 Report on the Operation of the Aged Care Act 1997, p 59, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2018-19-ROACA.pdf

There was continued growth in Australian Government expenditure for the Multi-purpose Service, from \$159.5 million in 2016–17 to \$168.8 million in 2017–18, with the amount spent in Queensland increasing by 6.8 per cent.⁸²²

8.1.5 Innovative Care Program

Innovative care was originally established in 2001-02 to pilot new approaches to providing aged care, for example, to support people with aged care needs who lived in state or territory-funded supported accommodation facilities who were at risk of entering residential aged care.⁸²³

The program is now closed, with no new entrants accepted since 2006. At 30 June 2019, there were eight projects, delivered through three services in New South Wales, two in South Australia, and one each in Tasmania, Victoria and Western Australia, at a cost of \$1.1 million in the form of a flexible care subsidy specific to each service. With no new entrants the number of care recipients is gradually decreasing as people leave. At 30 June 2019, there were 41 operational innovative care places, compared to 54 at 30 June 2018.⁸²⁴

8.1.6 National Aboriginal and Torres Strait Islander Flexible Aged Care Program

The National Aboriginal and Torres Strait Islander Flexible Aged Care Program is a grant funded program, with service providers entering into grant agreements with the Australian Government.⁸²⁵

The program also provides flexible aged care and culturally appropriate residential aged care to older Aboriginal and Torres Strait Islander people close to home and community. Services are located mainly in rural and remote areas and can include residential, home care or home support services.⁸²⁶ Care can be provided on a permanent or short-term basis and respite care on either an emergency or planned basis.⁸²⁷

⁸²¹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 14.

⁸²² Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 59, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2018-19-ROACA.pdf.

⁸²³ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 14.

⁸²⁴ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 60, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2018-19-ROACA.pdf.

⁸²⁵ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 15.

⁸²⁶ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 15.

⁸²⁷ Australian Government, My Aged Care, Support for Aboriginal and Torres Strait Islander people, <https://www.myagedcare.gov.au/support-aboriginal-and-torres-strait-islander-people>.

Services funded under the program are administered outside the Aged Care Act.⁸²⁸ In 2018-19, funding of \$44.1 million was provided to 35 services to deliver 1,072 aged care places. There were six services in Queensland at 30 June 2019 to deliver 109 aged care places.⁸²⁹

In the 2018-19 Budget, the Australian Government announced additional funding of \$105.7 million over four years to expand the program. Applications to expand or establish new services opened in October 2018.⁸³⁰

8.2 Other support programs

8.2.1 National Aged Care Advocacy Program

The Australian Government funds the National Aged Care Advocacy Program (NACAP) which provides free, confidential and independent advice for older people (and their representatives) receiving, or seeking to receive, Australian Government-funded aged care services.⁸³¹

Since July 2017, the Older Persons Advocacy Network (OPAN) has been engaged to deliver NACAP as a single national provider. OPAN delivers NACAP through its network of nine service delivery organisations across Australia. In 2018-19, OPAN delivered 2,564 education sessions and 16,169 instances of advice or individual advocacy.⁸³²

In 2018-19, Australian Government funding for NACAP was approximately \$10.6 million up from \$9.1 million in 2017-18.⁸³³

8.2.1.1 *Issues with the National Aged Care Advocacy Program*

The Public Advocate raised the issue of funding for the NACAP, submitting:

*It is critical that the NACAP is adequately funded to meet current and future demand for aged care advocacy services. Insufficient funding of advocacy services could become a significant barrier to aged care residents being able to seek redress for mistreatment and abuse and to access consumer protection mechanisms.*⁸³⁴

The QNMU suggested that one area where the Queensland Government could drive improvements in aged care delivery is in the area of advocacy for older Queenslanders. The QNMU proposed the following as potential approaches:

- *In conjunction with the States and Territories, the Commonwealth fund an Aged Care Ombudsman/Commissioner Office to assist consumers of aged care as they encounter issues in dealing with this complex system. It is anticipated that this Ombudsman/Commissioner role would work in a co-regulatory capacity with the Aged Care Quality and Safety Commission in*

⁸²⁸ Australian Government, Department of Health, 2017-18 Report on the Operation of the *Aged Care Act 1997*, p 40, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁸²⁹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 15; Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 60, 61 https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2018-19-ROACA.pdf.

⁸³⁰ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 15.

⁸³¹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 16.

⁸³² Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 19, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9319.pdf.

⁸³³ OPAN, Annual Report 2018-19, p 49, https://opan.com.au/wp-content/uploads/2020/01/OPAN_Annual-Report_2018-19_V6_HRes.pdf; Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 16.

⁸³⁴ Submission 1208, p 7.

a similar way to existing coregulatory models in other parts of the health care system, e.g. the Queensland Office of the Health Ombudsman. A state based approach is suggested as this brings the function closer to those who would use the system and acknowledges that each state and territory jurisdiction has its own idiosyncrasies;

- *Funding for advocacy services must be increased. Again, the experience of the QNMU is that significant advocacy resources are required to assist older Australians to effectively utilise the aged care system, and while advocacy organisations working in this space are highly effective, they do have capacity and funding constraints such that people do still fall through the cracks. Failure to fund advocacy services to assist those using the aged care system is simply false economy which leads to poor outcomes for individuals and ultimately increases the funding burden for all; and*
- *A requirement of any funding must be that the advocacy group is independent and not subject to influence by other organisations. Specific consideration should be given to Primary Health Networks, locality based advocacy services and special needs areas such as advocacy services servicing culturally and linguistically diverse communities.*⁸³⁵

In evidence for the investigation into the sudden closure of the Earle Haven residential aged care facility, the need to establish an ageing commissioner in Queensland was also raised by the Chief Executive Officer of ADA Australia:

*...we need to give consideration to whether there is a role for an ageing commissioner within Queensland. We have seen the development of that role in New South Wales—only just—and within Victoria it was about 12 months ago. As we are seeing more Queenslanders age, as we are seeing the difficulties that they are having in having their voice heard, I think it is imperative that the state government takes the lead on addressing those concerns.*⁸³⁶

8.2.2 Community Visitor Scheme

The Community Visitor Scheme (CVS) program provides companionship through one-on-one volunteer visits to consumers of residential aged care, home care packages and groups in residential aged care who are socially isolated or are at risk of social isolation or loneliness.⁸³⁷

In 2018-19, the Australian Government provided funding of \$18.0 million for the CVS. This supported approximately 12,000 volunteers who conducted around 240,000 visits.⁸³⁸

An open funding round was conducted from 1 May 2018 to 26 June 2018 for the delivery of the CVS from 1 January 2019 to 30 June 2021. The Grant Opportunity Guidelines for this round were designed to address issues identified in a review of the CVS, by:

- increasing uptake of the program in the home care sector
- improving information sharing between CVS providers
- increasing national consistency in the delivery of the program
- supporting innovative approaches to delivery.⁸³⁹

⁸³⁵ Submission 1213, p 23.

⁸³⁶ Public hearing transcript, Benowa, 12 September 2019, p 9.

⁸³⁷ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 16.

⁸³⁸ Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 19, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁸³⁹ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, pp 19-20, <https://www.gen->

8.2.2.1 *Issues with the Community Visitor Scheme*

Submitters who commented on the CVS referred to its potential for identifying elder abuse as well as the importance of building social connection as part of the continuum of care. For example, the Public Advocate compared the scope of the CVS with Queensland's Community Visitor Program for adults with impaired decision-making capacity as a means of reducing elder abuse, submitting:

The Commonwealth-funded aged care community visitor scheme also has potential to reduce the incidence of elder abuse in aged care. At present, the Commonwealth scheme links volunteer community members with aged care residents for the purpose of companionship and friendship. These individuals may or may not have the skills or inclination to identify and address the mistreatment of residents appropriately and effectively.

*In contrast, the Queensland community visitor program for adults with impaired decision-making capacity employs community visitors to undertake regular announced and unannounced visits to specified accommodation sites for the purpose of monitoring service delivery. Queensland community visitors have legislative authority to undertake functions such as lodging and resolving complaints on behalf of residents with impaired decision-making capacity, talking with staff and residents to clarify issues and concerns, and reviewing documentation and programs relating to their support and care. Community visitors can lodge reports with the Office of the Public Guardian that provides the report to the service provider for follow-up action.*⁸⁴⁰

The Public Advocate recommended the Queensland Government advocate for the Australian Government to establish a fully funded aged care community visitor scheme (with paid employees, not volunteers) based on the Queensland Community Visitor Program under the *Public Guardian Act 2014* (Qld). The Public Advocate stated that such a program, along with an expanded NACAP as referred to in section 8.2.1, would 'form a significant part of a comprehensive government response to elder abuse in residential and community-based aged care services'.⁸⁴¹

8.2.3 **Dementia and Aged Care Services Fund**

Through the Dementia and Aged Care Services Fund (DACS Fund), the Australian Government provides flexible funding to deliver new and innovative, generally time-limited projects that address aged care priority areas and help strengthen the aged care system. This includes research and innovation activities focusing on areas such as:

- older Australians with dementia and people at risk of dementia
- older Australians with diverse social and cultural care needs, and
- projects to support older Aboriginal and Torres Strait Islander people.⁸⁴²

The DACS Fund provides support for existing and emerging priorities in dementia care, special measures to support Aboriginal and Torres Strait Islander people, and ensuring people from diverse backgrounds receive the same quality of aged care as other senior Australians.⁸⁴³

[agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf](https://www.agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf).

⁸⁴⁰ Submission 1208, p 42.

⁸⁴¹ Submission 1208, p 8.

⁸⁴² Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 16.

⁸⁴³ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 75, https://www.agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

The DACS Fund provides funding for most of the dementia support programs (see below). There is a separate appropriation for the Severe Behaviour Response Teams.⁸⁴⁴

The DACS Fund also includes funding for the Remote and Aboriginal and Torres Strait Islander Aged Care Service Development Assistance Panel. The panel provides assistance to eligible Aboriginal and Torres Strait Islander service providers and/or those located in remote or very remote areas, supporting them to build capacity and improve the quality of aged care services and provide culturally appropriate services.⁸⁴⁵

The Australian Government has allocated \$351.6 million for the DACS Fund over the period, 2018-22.⁸⁴⁶

8.2.4 Dementia support programs

The Australian Government funds a range of programs that support the aged care sector to provide quality care to people living with dementia, including the 24-hour Dementia Behaviour Management Advisory Service (DBMAS), the rapid response Severe Behaviour Response Teams (SBRT) and the Dementia Training Program.⁸⁴⁷

8.2.4.1 *Dementia Behaviour Management Advisory Service*

The DBMAS is the first tier in the government's suite of support programs for carers of people experiencing behavioural and psychological symptoms of dementia (BPSD). In 2018-19, DBMAS provided support for 18,991 cases, (an increase of 23 per cent on the previous year).⁸⁴⁸

8.2.4.2 *Severe Behaviour Response Teams*

The second tier, and building on the DBMAS, the SBRTs are a mobile workforce of clinical experts who provide timely and expert advice to residential aged care providers who request assistance in caring for people with the most severe behavioural and psychological symptoms of dementia. The Australian Government is providing \$30.8 million over two years from 2019-20 to 2020-21 for this service.⁸⁴⁹

In 2018-19, SBRTs provided long term case management including detailed clinical assessment, recommendations for intervention and multiple on-site visits for 795 cases (a 12 per cent increase on the previous year). Both DBMAS and SBRTs had approximately 69 per cent of referrals from major cities and 31 per cent from regional and remote areas.⁸⁵⁰

8.2.4.3 *Other programs*

The Australian Government also funds Dementia Australia to deliver the National Dementia Support Program. This program provides a range of information, training and education programs and psychosocial support to people living with dementia, and their carers or families. The program also

⁸⁴⁴ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 16.

⁸⁴⁵ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 16.

⁸⁴⁶ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 72, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁸⁴⁷ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 17.

⁸⁴⁸ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, pp 75-76, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁸⁴⁹ Australian Government, Department of Health, 2017-18 Report on the Operation of the *Aged Care Act 1997*, p 47, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁸⁵⁰ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 76, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

aims to improve awareness and understanding about dementia in the general community.⁸⁵¹ The National Dementia Support Program offers a website and national helpline, where professional counselling or group and individual support sessions can be scheduled.⁸⁵²

In addition, the Australian Government has developed the Specialist Dementia Care Program (SDCP), with the aim of establishing at least one specialist dementia care unit in each of the 31 PHN regions.⁸⁵³ The aim of the units is to support people with very severe behavioural and psychological symptoms of dementia who cannot be cared for in a mainstream residential aged care facility. The SDCP provides specialised care for people:

- who live with very severe dementia complicated by physical aggression or other behaviours
- whose residential care facility or carers cannot manage the behaviours, even with help from other services.⁸⁵⁴

The SDCP uses a care model which includes person-centred care from staff with dementia training, support from specialist services in a small, cottage-like, dementia-friendly living environment.⁸⁵⁵

The SDCP will be implemented using a phased approach, with funding for the first 14 specialist dementia care units advertised early 2019. These units are expected to be operational by early 2020. Subject to evaluation outcomes, a further selection process for an additional 20 sites will be undertaken in 2021.⁸⁵⁶ By 2022–23, the Department of Health expects to have at least one SDCP unit in each of the 31 Primary Health Network regions.⁸⁵⁷

8.2.5 Dementia Research

In 2014–15, the Australian Government invested \$200 million over five years for dementia research through the Boosting Dementia Research Initiative. As part of this initiative, the National Health and Medical Research Council National Institute for Dementia Research was established to target, co-ordinate and translate the national research.⁸⁵⁸

8.2.6 Commonwealth Continuity of Support Programme

The Commonwealth Continuity of Support (CoS) Programme supports older people (65 years and over, and Aboriginal and Torres Strait Islander people aged 50 years and over) who are currently receiving

⁸⁵¹ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 20, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁸⁵² Australian Government, Department of Health, 2018–19 Report on the Operation of the *Aged Care Act 1997*, p 20, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁸⁵³ Australian Government, Department of Health, Specialist Dementia Care Program framework, https://www.health.gov.au/sites/default/files/documents/2019/12/specialist-dementia-care-program-framework_0.pdf.

⁸⁵⁴ Australian Government, Department of Health, Specialist Dementia Care Program framework, https://www.health.gov.au/sites/default/files/documents/2019/12/specialist-dementia-care-program-framework_0.pdf.

⁸⁵⁵ Australian Government, Department of Health, Specialist Dementia Care Program (SDCP), <https://www.health.gov.au/initiatives-and-programs/specialist-dementia-care-program-sdcp>.

⁸⁵⁶ Australian Government, Department of Health, Specialist Dementia Care Program framework, https://www.health.gov.au/sites/default/files/documents/2019/12/specialist-dementia-care-program-framework_0.pdf.

⁸⁵⁷ Australian Government, Department of Health, Specialist Dementia Care Program (SDCP), <https://www.health.gov.au/initiatives-and-programs/specialist-dementia-care-program-sdcp>.

⁸⁵⁸ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 17.

state-managed specialist disability services but are ineligible for the National Disability Insurance Scheme (NDIS) due to their age at the time the NDIS is implemented in a region.⁸⁵⁹

The CoS Programme aims to ensure that older people with disability continue to be supported to achieve similar outcomes to those they were achieving prior to the transition. It is an ongoing, 'grandfathered' program and will support approximately 8,500 older people. Once the NDIS completes its rollout in a region, there will be no new entrants to the CoS Programme.⁸⁶⁰

In 2017-18, the Australian Government provided funding of \$117.7 million for the program.⁸⁶¹

8.2.7 Special needs support programs

Nine groups of people are identified as having special needs under the Aged Care Act. This includes Indigenous Australians, people from culturally and linguistically diverse (CALD) backgrounds, lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ+) people, veterans and people who live in rural or remote areas. As part of the planning process described below, the Department of Health can decide that a number of residential or flexible places will be made available to focus on the care of one or more of these groups. The Government also funds a number of supplements, strategies and programs to meet the needs of these groups. For example:

- a Partners in Culturally Appropriate Care organisation is funded in each state and territory to help aged care providers deliver culturally appropriate care to clients from CALD backgrounds, and to assist these clients in accessing care
- the National LGBTI Ageing and Aged Care Strategy includes a number of goals and actions to improve the aged care system for LGBTI people
- aged care providers caring for individual clients who are veterans, in financial hardship, or homeless can receive supplements to the base funding for these clients in specified circumstances
- a viability supplement is paid to aged care providers in rural and remote areas, as well as providers of specialist services to Indigenous or homeless clients, to assist with the higher costs of providing care in these areas.⁸⁶²

Further information on accessibility to aged care services for people with special needs can be found in Chapter 9.

8.3 Department of Veterans' Affairs - aged care programs

In addition to the Department of Health, the Department of Veterans' Affairs (DVA) also offers aged care programs. These include the gold and white treatment cards for veterans, their war widows and widowers and dependents. There were 13,392 gold or white treatment card holders in residential care at 30 June 2019, a decrease of 1,995 from 30 June 2018.⁸⁶³

The DVA also manages a number of in-home care and support programs for eligible DVA clients, including the Veterans' Home Care Program and the Community Nursing Program, which aim to

⁸⁵⁹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 17.

⁸⁶⁰ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 17.

⁸⁶¹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 17.

⁸⁶² Parliament of Australia, Parliamentary Library, Research Paper Series, 2016–17 Aged Care: a quick guide, https://parlinfo.aph.gov.au/parlInfo/download/library/prspub/4894104/upload_binary/4894104.pdf.

⁸⁶³ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 68, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

support DVA clients to remain independent in their homes and improve their quality of life and health.⁸⁶⁴

Eligibility for DVA in-home care and support programs is linked to a DVA client's statutory entitlement under the *Safety, Rehabilitation and Compensation (Defence-Related Claims) Act 1988* (Cth), the *Military Rehabilitation and Compensation Act 2004* (Cth) or the *Veterans' Entitlements Act 1986* (Cth) and program specific criteria.⁸⁶⁵ There is no minimum age requirement.⁸⁶⁶

8.3.1 Veterans' Home Care Program

The Veterans' Home Care (VHC) Program provides a range of home care services for DVA clients with low care needs. VHC Program services include domestic assistance, personal care, respite care and safety-related home and garden maintenance.

VHC Program services are provided to eligible DVA clients on a needs basis as assessed by contracted VHC Assessment Agencies. If VHC services are approved, VHC Assessment Agencies will co-ordinate a contracted VHC Service Provider to deliver the services.

In 2017-18, the Australian Government provided funding of \$109.4 million for VHC Program services for approximately 49, 100 clients. Approximately 96% of VHC clients are over 65 years, with an average age of 83 years.⁸⁶⁷

8.3.2 Community Nursing (CN) Program

DVA's Community Nursing Program is designed to enhance the independence and health outcomes of DVA clients by avoiding early admission to hospital and/or residential care through access to CN services that meet their assessed clinical and/or personal care needs.⁸⁶⁸

DVA clients can access the CN program via referral to a contracted CN provider from a general practitioner, nurse practitioner, treating doctor in hospital, hospital discharge planner or VHC Assessment Agency.⁸⁶⁹

In 2017-18, the Australian Government provided funding of \$133 million for CN Program services for 18,500 clients. Approximately 98 per cent of CN clients are over 65 years.⁸⁷⁰

Committee comment

Flexible care

The Australian Governments invested \$516 million in 2017-18 on a suite of flexible care programs designed to provide alternative approaches to residential and home-based aged care. These programs provide 9,644 places nationally across a range of transitional care, short term, multi-purpose and innovative care programs in addition to the National Aboriginal and Torres Strait Islander Flexible Aged Care program.

Other support programs

The Older Persons Advocacy Network has been engaged to deliver advocacy services for the Australian Government's National Aged Care Advocacy Program since 2017. Advocacy support is essential to ensure that older people and their families have access to confidential and independent information

⁸⁶⁴ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 18.

⁸⁶⁵ The Act that an individual is eligible under is determined by the period(s) and type(s) of service rendered.

⁸⁶⁶ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 18.

⁸⁶⁷ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 18.

⁸⁶⁸ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 18.

⁸⁶⁹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 18.

⁸⁷⁰ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 18.

about aged care matters. This is valuable work to assist people protect their rights and interests in aged care.

The Community Visitor Scheme

In 2018-19, the Australian Government provided funding of \$18.0 million for the Community Visitor Scheme which supports volunteer visits to residents in residential aged care facilities, people receiving home based aged care and groups in care who are at risk of social isolation. During the year, volunteers conducted around 240,000 such visits. This program should be continued.

The Australian Government should consider establishing a funded aged care community visitor scheme, based on the Queensland community visitor program under the *Public Guardian Act 2014* (Qld), to help identify incidences of elder abuse and provide support to aged care clients who may be at risk of elder abuse.

Recommendation 23 Establishment of a funded aged care community visitor scheme

The committee recommends that the Australian Government consider establishing a funded aged care community visitor scheme to help address risks of elder abuse for older people receiving aged care.

9 Accessibility for people with special needs

In relation to people with special needs, the Department of Health advised the committee:

One of the objectives of the aged care system is to facilitate access to aged care services by those who need them, regardless of race, culture, language, gender, economic circumstance or geographic location. Nine special needs groups are set out in section 11-3 of the Aged Care Act 1997:

- *people from Aboriginal and Torres Strait Islander communities*
- *people from culturally and linguistically diverse backgrounds (CALD)*
- *people who live in rural or remote areas*
- *people who are financially or socially disadvantaged*
- *veterans*
- *people who are homeless or at risk of becoming homeless*
- *care-leavers*
- *parents separated from their children by forced adoption or removal*
- *lesbian, gay, bisexual, transgender and intersex (LGBTI) people.*⁸⁷¹

*Consumers from some special needs groups can attract higher payments in the form of supplements, e.g. Viability Supplement (for services operating in rural and remote areas and/or those providing services to Aboriginal and Torres Strait Islander people), the Veterans' Supplement, and the Homeless Supplement.*⁸⁷²

On 6 December 2017, the Aged Care Diversity Framework (the Framework) was launched. The Framework seeks to embed diversity in the design and delivery of aged care, and support action to address perceived or actual barriers to consumers accessing safe, equitable and quality aged care. The Framework builds on the previous National LGBTI Ageing and Aged Care Strategy and the National Ageing and Aged Care Strategy for People from CALD Backgrounds.

According to the Department of Health, the Diversity Sub-Group of the Aged Care Sector Committee, which developed the Framework, has also undertaken extensive consultation on three initial action plans to sit under the Framework for:

- people from Aboriginal and Torres Strait Islander communities
- people from CALD backgrounds
- LGBTIQ+ people.

In February 2019, an action plan for older Aboriginal and Torres Strait Islander people was launched. The action plan is proposed to assist the aged care sector to address barriers and challenges faced by older Aboriginal and Torres Strait Islander people when accessing and receiving aged care.

A National Advisory Group for Aboriginal and Torres Strait Islander Aged Care has been established to advise government on the needs and views of older Aboriginal and Torres Strait Islander people in the

⁸⁷¹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 10.

⁸⁷² Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 10.

development and implementation of Government ageing and aged care policies, programs and strategies.⁸⁷³

9.1 People from Aboriginal and Torres Strait Islander communities

Broadly speaking, older Aboriginal and Torres Strait Islander people have proportionally higher representation in non-flexible home care services and proportionally lower representation in non-flexible residential care services, relative to the total aged care target population. The number of Indigenous Australians accessing home care increased by 42 per cent from 2016-17 to 2017-18, while the number of Indigenous Australians accessing residential care and home support increased by two per cent and one per cent respectively.⁸⁷⁴

Funding for special measures for Aboriginal and Torres Strait Islander people is also provided under the DACS Fund. Eligible aged care providers can also receive specialist advice and assistance via the Remote and Aboriginal Torres Strait Islander Aged Care Service Development Assistance Panel.⁸⁷⁵

Flexible models of care are provided under the National Aboriginal and Torres Strait Islander Flexible Aged Care Program, as outlined earlier.

9.2 People from culturally and linguistically diverse backgrounds

Australia has a culturally diverse population, and according to the Department of Health many people from culturally and linguistically diverse (CALD) backgrounds are seeking culturally appropriate aged care. To assist them, the My Aged Care website provides translated material in 18 languages. In 2017-18, there were 22,812 visits to the translation pages.⁸⁷⁶ An action plan for older people from CALD backgrounds was launched in February 2019 to assist the aged care sector to address barriers and challenges faced by older people from CALD backgrounds when accessing and receiving aged care. Copies of the supporting consumer resource are available in 26 languages.⁸⁷⁷

There were 22,525 older Australians from CALD backgrounds in a home care package as at 30 June 2018, representing around 25 per cent of total home care consumers. In residential care, as at 30 June 2018, there were 35,557 older Australians from CALD backgrounds in permanent or respite care, which represents around 19 per cent of all residents. This proportion has been stable in recent years for both home care and residential care. In 2017-18, 155,905 consumers from a CALD background accessed home support, up from 146,571 in 2016-17.⁸⁷⁸

⁸⁷³ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, pp 64-64, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁸⁷⁴ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 54, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁸⁷⁵ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 42, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁸⁷⁶ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 53, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

⁸⁷⁷ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 66, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2018-19-ROACA.pdf.

⁸⁷⁸ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 53, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

Broadly speaking, people from CALD backgrounds have proportionally higher representation in home care services and proportionally lower representation in residential care services.⁸⁷⁹

A major program supporting CALD communities is the Partners in Culturally Appropriate Care program. In Queensland, the Partners in Culturally Appropriate Care program is delivered by Diversicare, a division of the Ethnic Communities Council of Queensland. Diversicare aims to equip aged care service providers to deliver culturally appropriate care to older people from culturally and linguistically diverse communities.⁸⁸⁰

Funding to better support services targeting CALD people is also provided through the DACS.

9.3 People in rural and remote areas

Providers face a number of extraordinary challenges in delivering aged care services in rural and remote areas.

These challenges can include issues related to the operation of small services which may be remote from professional assistance and support. There may also be higher infrastructure and supply costs and difficulties in attracting and retaining staff. In recognition of these challenges, the department administers the Peer and Professional Support Program to provide funding to assist aged care providers delivering services to Aboriginal and Torres Strait Islander people located anywhere in Australia, and aged care providers located in remote and very remote areas.⁸⁸¹

Support provided to consumers in rural and remote areas to access aged care services includes:

- the viability supplement scheme for small, remote and very remote residential care services as well as for eligible home care recipients
- flexible aged care programs such as the Multi-Purpose Services Program and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program
- providing funds through the DACS Fund, including the Remote and Aboriginal and Torres Strait Islander Aged Care Service Development Assistance Panel program.⁸⁸²

Issues with the delivery of aged care services for people in rural and remote areas have been identified in Chapter 9.

9.4 People who are financially or socially disadvantaged

The Aged Care Act enables older Australians to access residential care, regardless of their capacity to make accommodation payments. An accommodation supplement is payable for people who are unable to pay all or part of their accommodation costs, including low-means, supported, concessional and assisted residents, and certain residents approved under the hardship provisions. To receive the maximum amount of accommodation supplement payable for a supported resident, a service must have a supported-resident ratio (counting all residents defined as relevant residents as per the Subsidy Principles 2014, but excluding extra service places) of more than 40 per cent of total residents. If a

⁸⁷⁹ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 6, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9318.pdf.

⁸⁸⁰ <http://www.diversicare.com.au/service-providers/partners-in-culturally-appropriate-care/>.

⁸⁸¹ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 43, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%9318.pdf.

⁸⁸² Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 67, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2018-19-ROACA.pdf.

service does not meet this ratio, then the amount of accommodation supplement paid is reduced by 25 per cent.⁸⁸³

Hardship assistance is payable if the person can demonstrate to the Department of Human Services that they are in financial hardship as a result of paying their aged care fees and essential expenses. The Australian Government provided \$6.6 million in hardship supplements for residential care and home care during 2018–19.⁸⁸⁴

9.5 People who are homeless or at risk of becoming homeless

In 2018–19, services that support older Australians who are homeless, or at risk of becoming homeless, were funded through the Commonwealth Home Support Programme.⁸⁸⁵

As part of the viability supplement, support is available for eligible residential services specialising in care for people at risk of homelessness, low-care in rural and remote areas, and care for Aboriginal and Torres Strait Islander Australians. The homeless supplement is also paid to support eligible aged care homes that specialise in caring for people with a history of, or who are at risk of, homelessness.⁸⁸⁶

9.6 Care Leavers

A care-leaver is a person who was in institutional care or other form of out-of-home care, including foster care, as a child and/or youth. This includes the Forgotten Australians, Former Child Migrants and Stolen Generations. People known as Forgotten Australians are now reaching an age where they may require aged care services and many find traumatic childhood memories and fears return when they think about their aged care.⁸⁸⁷

The Australian Government has funded Helping Hand Aged Care for a project to help Forgotten Australians understand and engage with aged care services, and help aged care providers respond appropriately to their needs. The project builds on an information package launched by the Government in 2016 to raise awareness of the specific care needs of care-leavers among aged care service providers.⁸⁸⁸

9.7 LGBTIQ+ community

The Department of Health states that people who identify as LGBTIQ+ have ‘specific needs, particularly as they age, stemming from decades of inequitable treatment and social isolation as a result of stigma and family rejection’.⁸⁸⁹

The Department of Health launched an action plan for LGBTIQ+ older Australians in February 2019 under the Aged Care Diversity Framework. The action plan has been designed to ‘assist the aged care sector to address barriers and challenges faced by older LGBTIQ+ people when accessing and receiving aged care’. The LGBTI Health Alliance receives the funding to undertake national co-ordination and

⁸⁸³ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 68, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2018-19-ROACA.pdf.

⁸⁸⁴ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 68, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2018-19-ROACA.pdf.

⁸⁸⁵ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 69, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2018-19-ROACA.pdf.

⁸⁸⁶ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 69, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2018-19-ROACA.pdf.

⁸⁸⁷ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 69, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2018-19-ROACA.pdf.

⁸⁸⁸ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 69, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2018-19-ROACA.pdf.

⁸⁸⁹ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 70, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2018-19-ROACA.pdf.

support activities to promote the well-being of older LGBTIQ+ people, and deliver national LGBTI aged care awareness training. The DACS Fund also provides funding to better support services targeting LGBTIQ+ people.⁸⁹⁰

9.8 Other people with special needs

Although not recognised as one of the nine special needs groups set out in the Aged Care Act, the following groups can face difficulties accessing appropriate care to meet their needs. The following provides a summary of the assistance available, or the importance of meeting the needs of these groups.

9.8.1 People with disabilities

Aged care services that provide support for older people with a disability include:

- home maintenance and modifications including repairs, garden maintenance, and installation of handrails and ramps
- goods and equipment such as a walking frame or raised toilet seat
- allied health including occupational therapy, dietitian services, and physiotherapy
- respite care in a community centre or an aged care home
- Independent Living Centres, which have products and equipment to help manage disabilities in daily life.⁸⁹¹

For those people with a disability who wish to stay living at home, there are a number of programs available, depending on eligibility. People who start the NDIS before age 65 may choose to keep receiving services under the scheme as they age.⁸⁹²

If a person with disability is an existing client of state specialist disability services, is 65 years and over or 50-64 years if an Aboriginal and Torres Strait Islander person, and not eligible for the NDIS, then they may be eligible for the Continuity of Support Programme (CoS). The CoS provides funding for the following services:

- accommodation support
- community support
- community access
- respite care
- individual support packages.⁸⁹³

However, for those diagnosed with a disability at 65 years or over, support services are provided through the CHSP or through a home care package.⁸⁹⁴

⁸⁹⁰ Australian Government, Department of Health, 2018-19 Report on the Operation of the *Aged Care Act 1997*, p 70, https://www.gen-agedcaredata.gov.au/www_aihngen/media/ROACA/2018-19-ROACA.pdf.

⁸⁹¹ Australian Government, My Aged Care, Caring for someone with a disability, <https://www.myagedcare.gov.au/caring-someone-disability>.

⁸⁹² Australian Government, My Aged Care, Support for people with disabilities, <https://www.myagedcare.gov.au/support-people-disabilities>.

⁸⁹³ Australian Government, Department of Health, About the Commonwealth Continuity of Support Programme, <https://www.health.gov.au/initiatives-and-programs/commonwealth-continuity-of-support-cos-programme/about-the-commonwealth-continuity-of-support-programme>.

⁸⁹⁴ Australian Government, My Aged Care, Support for people with disabilities, <https://www.myagedcare.gov.au/support-people-disabilities>.

9.8.2 People with dementia and mental health issues

Information on dementia and its prevalence can be found in section 2.2.5, while information on programs for those with dementia can be found in section 8.2. At 30 June 2018, just over half of all residential aged care residents with an ACFI assessment had a diagnosis of dementia.⁸⁹⁵

Mental health may refer to problems such as stress, anxiety, depression or dependence on alcohol and/or drugs. A person experiencing one or more of these problems may not meet the diagnostic criteria for a mental disorder. Older people with a diagnosis of a mental illness or mental disorder may find their illness varies in both duration and severity, and may interfere with an individual's cognitive, social and emotional abilities.⁸⁹⁶

There is an increasing recognition that good mental health is an important factor in healthy ageing. However, the mental health of an individual is determined by a combination of psychological, biological, and/or social and cultural factors, as well as timely access to appropriate and effective clinical and non-clinical services.⁸⁹⁷

According to the Australian Institute of Health and Welfare the mental health of older people may also be affected by factors such as:

*...losing the ability to live independently, experiencing bereavement (particularly with death of a life partner), and a drop in income following retirement from the labour force. These factors may lead to social isolation and/or loneliness, loss of independence and increased psychological distress...When dementia and depression occur at the same time, it can be difficult to distinguish between them, as the signs and symptoms are similar. For example, memory or concentration problems can be symptoms of both depression and dementia.*⁸⁹⁸

9.8.3 Young people in aged care facilities

Younger people with disability who haven't obtained appropriate housing and support have historically moved into residential aged care as a last resort. The reasons younger people are living in aged care facilities include the complexity of their health needs, meaning they have difficulty accessing appropriate health supports in other settings, and the lack of suitable housing.⁸⁹⁹

Young people in aged care continues to be an issue for the Australian Government. According to the Summer Foundation, over the 2017–18 financial year, a total of 2,187 younger people entered residential aged care.⁹⁰⁰ As at 30 September 2018, the Department of Health reported there were

⁸⁹⁵ Australian Government, Department of Health, 2017–18 Report on the Operation of the *Aged Care Act 1997*, p 6, https://www.gen-agedcaredata.gov.au/www_aihwen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

⁸⁹⁶ Australian Institute of Health and Welfare, *Australia's Welfare 2015*, <https://www.aihw.gov.au/getmedia/c2ff6c58-e05e-49ed-afd7-43bd21eef4e2/AW15-6-4-Mental-health-of-older-Australians.pdf.aspx>.

⁸⁹⁷ Australian Institute of Health and Welfare, *Australia's Welfare 2015*, <https://www.aihw.gov.au/getmedia/c2ff6c58-e05e-49ed-afd7-43bd21eef4e2/AW15-6-4-Mental-health-of-older-Australians.pdf.aspx>.

⁸⁹⁸ Australian Institute of Health and Welfare, *Australia's Welfare 2015*, <https://www.aihw.gov.au/getmedia/c2ff6c58-e05e-49ed-afd7-43bd21eef4e2/AW15-6-4-Mental-health-of-older-Australians.pdf.aspx>.

⁸⁹⁹ https://www.dss.gov.au/sites/default/files/documents/03_2019/younger-people-aged-care-infographic.pdf.

⁹⁰⁰ Summer Foundation, *Younger People in Residential Aged Care: True Stories, Practical Solutions*, 2019, p 13.

5,905 people aged under 65 living in residential aged care facilities across Australia. Of these, 188 were aged under 45, and 30 were aged under 35 years.⁹⁰¹

The NDIS Report Card for June 2018, prepared by the Summer Foundation, highlights the six most important outcomes for the NDIS to achieve for young people, with reducing the numbers living in residential aged care listed as outcome number one. This is in part because living in a RACF reduces young people's independence, limits their ability to reach their potential and can be socially isolating. Aged Care Guide states that '82 percent of younger people in residential aged care rarely or never visit their friends and around 13 percent never go outside'.⁹⁰²

9.9 Issues for people with special needs

A number of stakeholders commented on the imperative to consider the diverse needs of older people with special needs. For example, Queensland PHNs referred to the importance of considering the differing care needs of each individual, stating:

*This is of particular importance for vulnerable groups such as Aboriginal and Torres Strait Islander people, culturally and linguistically diverse groups, people living with mental illness or cognitive impairment and people who have experienced trauma.*⁹⁰³

Equity of access for people with special needs was raised as an important issue in the delivery of aged care. The QNMU advised that special needs groups, such as those from CALD communities, the indigenous community and the LGBTIQ+ communities, often feel marginalised and disenfranchised.⁹⁰⁴

The Cairns Community Legal Centre Inc explained access can be more difficult for people with special needs in a system that is already challenging and complex to navigate:

*In relation to those older persons who have special needs, there are a raft of issues that individually affect the different groups or categories of older persons with special needs. These issues range from accessibility of services due to locality or homelessness to carers resources and availability to provide culturally and linguistically appropriate services...it is noted we see many older persons who do face these barriers when attempting to navigate the already complicated and complex nature of the aged care system.*⁹⁰⁵

Queensland PHNs addressed equity of access and reasons why such groups may have trouble accessing services, and also commented on the impact it has on service providers, telling the committee:

Older people who experience disadvantage do not have the same equity of access to in-home and residential aged care services as other older people in the community. This includes older people from culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander people, those who are homeless or at risk of homelessness, those with cognitive impairment and those experiencing mental illness.

These older people may be unlikely to proactively access services, i.e. they are not going to ring a call centre or provide their personal details over the phone. Many are also resistant to and untrusting of government and service providers and reticent in regard to institutionalised care.

Currently the system relies on community service providers facilitating access to aged care services for older people who experience disadvantage. Service providers are not paid for this

⁹⁰¹ Australian Government, Younger People in Residential Aged Care – Action Plan, p 1, https://www.dss.gov.au/sites/default/files/documents/03_2019/younger-people-aged-care-infographic.pdf

⁹⁰² <https://www.agedcareguide.com.au/talking-aged-care/younger-people-with-disability-in-aged-care>

⁹⁰³ Submission 1212, p 6.

⁹⁰⁴ Submission 1213, pp 12-13.

⁹⁰⁵ Submission 1276, p 2.

system facilitation role, despite them being best placed to support people experiencing vulnerability through their existing outreach models and established trusted relationships with communities.

In addition, it is challenging for these service providers to remain viable given their costs of delivering services and supporting older people experiencing vulnerability is already higher than commercial providers.

Without community service providers undertaking this service, it is anticipated that older people experiencing vulnerability would fall through the cracks and miss out on aged care services.⁹⁰⁶

The AASW Queensland Branch also advised that accessing the aged care system and getting the right support can be particularly challenging for people with complex care needs. They provided the following expanded list of people who may be the most vulnerable:

This includes older people who:

- exhibit challenging behaviours related, for example, to drug and alcohol abuse;*
- experience difficulties in engaging with the system, including those who will not seek or who would refuse assistance, even though they would benefit from support to remain living in the community;*
- are unable to identify or advocate for their support needs;*
- are deterred by the 'user pays' system and/or are experiencing financial hardship;*
- require assistance with service integration from multiple agencies;*
- with dementia, memory loss or cognitive impairment requiring specialised support;*
- with challenging domestic situations, such as where squalor and/or hoarding and self-neglect are issues;*
- at risk of or experiencing elder abuse;*
- require support with making informed choices and decision-making;*
- have mental health issues, especially those with persistent non-acute mental health issues; and*
- are from Aboriginal and Torres Strait Islander and culturally and linguistically diverse backgrounds.*

We note that while the aged care system is moving to be more focused on consumer choice, this is often limited for people with complex needs as there is little incentive for providers to take on complex clients.⁹⁰⁷

Ms Jane Smith commented on the availability of services for the diverse needs of older people, submitting:

My brother has intellectual, mental and physical disabilities and has been moved into Aged Care in April 2018. Our family has found a facility that has been able to meet all of his requirements through a Queensland Health residential care unit at Cleveland. Frankly, I believe this facility is very unique and I am grateful every day that there was capacity for my brother when the time came. Having researched other service providers, I am not convinced the breadth of care facilities required are available within Queensland. Across our population there is a diversity of needs,

⁹⁰⁶ Submission 1301, p 4.

⁹⁰⁷ Submission 1288, p 6.

*cultures and beliefs that most service providers - particularly for-profits, would struggle to provide.*⁹⁰⁸

Queensland PHNs commented on a lack of funding to help vulnerable people, stating:

*Many people who are vulnerable require support and assisted access into the system, which may include outreach, and this is all unfunded at present, relying on those providers with specialist staff and care models to provide assistance.*⁹⁰⁹

The following provides a summary of the issues raised by stakeholders in relation to particular groups of people with special needs.

9.9.1 Aboriginal and Torres Strait Islander people

Stakeholders raised a range of access and suitability issues in relation to how the aged care sector caters for Aboriginal and Torres Strait Islander people.

COTA Queensland noted that Aboriginal and Torres Strait Islander people are more likely to live outside major cities than their non-Indigenous counterparts, and that the problems faced in accessing services in rural and remote locations are greater for Aboriginal and Torres Strait Islander people. COTA Queensland stated:

Older members of Indigenous communities are often reluctant to leave their country and family to access aged care. The importance of older Indigenous people remaining close to their community is well document [sic]. They are likely to see residential facilities as a place where people are sent to die. The need to investigate effective approaches to ageing well in Indigenous communities has been largely ignored.

*Given that Indigenous people are more likely to suffer poor health outcomes, and given that services are typically poorer in regional and remote areas, this has important implications for ensuring equity of access to aged care.*⁹¹⁰

COTA Queensland advised that in providing aged care services to Aboriginal and Torres Strait Islander people, important issues to consider include:

- the geographical reach of providers
- the availability of Indigenous-specific services and services employing Indigenous health care workers
- the cultural competence of all aged care workers, and
- exploring ways to integrate aged care services into other culturally appropriate services.⁹¹¹

The cultural competence of staff to meet the needs of Aboriginal and Torres Strait Islander people was also raised as an issue by the RANZCP, who submitted:

*It is essential that aged care staff and health professionals providing support or mental health care recognise and respect the roles of older Aboriginal and Torres Strait Islander peoples and are aware that concepts of mental health are integrated into broader concepts of wellbeing within their cultures. All staff and health visitors should be aware of principles for working with Aboriginal and Torres Strait Islander peoples, and respond with flexibility in access and service delivery to meet their needs.*⁹¹²

⁹⁰⁸ Submission E188.

⁹⁰⁹ Submission 1301, p 2.

⁹¹⁰ Submission 1304, p 13

⁹¹¹ Submission 1304, p 13.

⁹¹² Submission 1207, attachment, p 3.

Aurukun Shire Council, who owns and manages the Chivaree Centre which provides services to 42 aged care residents, advised that the current challenges facing the provision of services and the sustainability of the service in the long term would include appropriate facilities and infrastructure and also workforce development.⁹¹³

The Healing Foundation raised concerns that:

*government policies and programs seemingly disregard the level of trauma in our communities, and in many instances, exacerbate that trauma by imposing service models that continue to marginalize and disempower Aboriginal and Torres Strait Islander people... The inquiry is an opportunity to emphasise the need to ensure Queensland policy and service systems provide culturally-responsive and trauma-informed care that meet the special needs of elderly Aboriginal and Torres Strait Islander people...Consistent with the vision of the Aged Care Diversity framework, and given the high level of trauma and disadvantage experienced by Stolen Generations, it is essential that strategies and systems aimed at ensuring quality of care systems for ageing Australians specifically highlight the special needs of elderly Stolen Generations survivors and their descendants.*⁹¹⁴

The Healing Foundation recommended that Queensland aged care policy, programs and services embed:

- *design, delivery and ongoing evaluation of cultural competency and trauma awareness training programs that address racism, ensure accountability and measure meaningful compliance within aged care services. This is not only critical to improve the quality of service provision, it is essential to avoid inflicting further trauma on an already vulnerable and marginalised client group.*
- *healing and trauma-informed approaches that are applied holistically to aged care services and support for Aboriginal and Torres Strait Islander people. Assistance to navigate the aged care system and to connect across service domains should be staffed by Aboriginal and Torres Strait Islander people who are trained in trauma-informed practice. Where they are supporting Stolen Generations, they should have specialist knowledge and preferably lived experience of the Stolen Generations.*
- *leadership, collaboration and coordination across all levels of government, the non-government sector, industry and, most importantly, Aboriginal and Torres Strait Islander people to promote and support trauma and healing-informed policies, programs and services for elderly Aboriginal and Torres Strait Islander people.*
- *urgent action to ensure that Stolen Generations can access aged care services and support that meet their complex needs and which do not re-traumatise survivors. Organisations supporting and providing services to Stolen Generations must adopt trauma-informed, culturally relevant approaches at all levels including in their underpinning policies and systems, as well as for individual workers.*
- *commitments to co-design of policy and programs, and to investments in community-led services and programs that are supported over the long-term, so that self-determination becomes a reality for Aboriginal and Torres Strait Islander communities. This means, for example, that initiatives taken to address the needs of the Stolen Generations must be led by Stolen Generations members and centred on the needs that they themselves have identified.*
- *recognition of the value of cultural knowledge and how it can inform policy formation and service delivery.*

⁹¹³ Submission 1308, p 2.

⁹¹⁴ Submission 1275, p 2.

- *a strong evidence base with a commitment to co-evaluation that informs and empowers local decision-making at all levels, including local models of aged care.*⁹¹⁵
- *The Royal Commission heard evidence about barriers for Aboriginal and Torres Strait Islander peoples accessing aged care services. These included:*
- *Some Aboriginal and Torres Strait Islander people are not aware of the range of aged care services to which they may be entitled.*
- *My Aged Care is not easily accessible to those who do not have English as their first language. The system also assumes a level of internet and phone access, or at least a reliable mail service. This is not realistic for a significant portion of Aboriginal and Torres Strait Islander people, particularly those who live in remote and very remote locations.*
- *Aged Care Assessment Team and Regional Assessment Services processes require an applicant to discuss intimate and personal health details. If the assessor is a stranger or does not use an interpreter or trusted cultural support worker, the applicant is unlikely to speak frankly or with the detail needed for a proper assessment.*
- *When Aboriginal and Torres Strait Islander people perceive that mainstream services are not culturally safe, they will avoid those services.*⁹¹⁶

Cultural safety was reported to be a critical issue for Aboriginal and Torres Strait Islander people.⁹¹⁷

9.9.2 Culturally and linguistically diverse communities

Despite efforts to better cater for CALD communities, stakeholders advised the committee that there is still much work to be done to provide equal access to aged care. For example, the RANZCP advised that there are limited appropriate care options for older people from CALD backgrounds and the current system still lacks sensitivity to this group, particularly in RACFs.⁹¹⁸

The AASW Queensland Branch submitted that CALD groups tend to face significant barriers to accessing and receiving quality aged care services, due to:

...lack of knowledge regarding service procedures, unmet cultural needs, and communication and language barriers for people from non-English speaking backgrounds. Language and other cultural barriers can limit people's early access to the aged care system, resulting in people accessing the aged care system in crisis, often through emergency services. These cultural nuances and assumptions are also not always picked up through the My Aged Care assessment process, which leads to older people from CALD backgrounds not receiving care that meets their needs. A common complaint in residential aged care facilities for multicultural clients is around food and completing rituals. This includes making coffee independently the way they are used to or having food that includes the spices and flavours of their culture. CALD older people may present with different psychosocial needs than others in aged care. Due to language barriers and cultural differences, this group are at increased risk of social isolation. In addition, many people from culturally and linguistically diverse backgrounds may not have familial support networks in Australia. Older migrants may experience serious mental health outcomes due to past migration

⁹¹⁵ Submission 1275, pp 2-3.

⁹¹⁶ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 168, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁹¹⁷ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 175, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁹¹⁸ Submission 1207, attachment, p 3.

*experiences and trauma, such as fleeing persecution or war. They may also be hesitant to access mental health services due to cultural stigma associated with mental illness.*⁹¹⁹

To address this issue, the AASW Queensland Branch suggested:

*Holistically meeting the diverse needs of this population of older people in our community requires an equally diverse workforce and flexibility in service delivery to cater to their needs. Models of care must go beyond simply providing physical care and consider people's spiritual and cultural needs. Meeting these needs are essential to improved health and wellbeing outcomes and quality of life.*⁹²⁰

The Pacific Islands Council of Queensland explained that because of cultural preferences, such as preferring to be cared for at home by family members, there are a number of things that can be done to improve this experience for the CALD community:

- provide help (information and financial) to family members to help care for their elderly at home
- continue to provide respite services to give the family carers a break, along with help in the latter part of the elderly's life when fulltime care of trained professionals is required
- develop strategies, in conjunction with CALD centred services and communities, for CALD elderly suffering from health issues that need fulltime professional assistance
- measures need to be implemented to limit any elder abuse for home cared Australians
- any review or restructuring of the aged care system should also include providing education on services and knowledge on healthcare programs for the elderly to all CALD communities, noting that having a designated staff for CALD clients in service organisation does not necessarily address this
- language needs for CALD elderly clients need to be incorporated into services
- staff ratio in services need to be reviewed - there is an increase of CALD workers in the aged care sector who may be able to assist but who are also made to work extra hours without proper staffing incentives, CALD staff will not speak out because they fear of losing their jobs.
- community groups could assist (at a cost) in social activities for elderly in nursing homes or to work with aged care providers to develop activities/programs for CALD elderly.⁹²¹

In evidence at the committee's Brisbane hearings, Mr Peter Last, Chief Executive Officer, Ethnic Communities Council of Queensland (ECCQ), including Diversicare Home Care and Berlasco Court Caring Centre, told the committee:

*ECCQ believes that everyone, irrespective of their background, should be able to age in the most dignified and culturally appropriate way. People from CALD backgrounds face very complex challenges when seeking aged-care services and are extremely vulnerable at end of life and during the palliative phases of their dying.*⁹²²

On the particular challenges of establishing a residential aged care facility that reflects multicultural values and serves the needs of ageing Chinese and other ethnic people in Brisbane, Mr Choe Lam Tan, Founder and Managing Director of Jeta Gardens, Bethania, told the committee:

⁹¹⁹ Submission 1288, pp 8, 9, 10.

⁹²⁰ Submission 1288, p 10.

⁹²¹ Submission E1876.

⁹²² Public hearing transcript, Brisbane, 18 October 2019, p 3.

I believe in multiculturalism. Because of that, the facility has to have a very balanced model so that it not only cares for the very profound needs of the ageing Asians but also cares for the wider community. This is how Jeta Gardens was formed.

*Asians have a cultural stigma. They would not, if they had a choice, allow their parents or themselves to come to a nursing home. It is bad; it is no good. So when I started this, the challenge was not so much the finance that I could raise but how I could win them over with a model that is appealing to them and yet is also appealing to the wider community—may I say, the Caucasian Australian.*⁹²³

9.9.3 Care-Leavers

The AASW called for an improvement to funding models to better care for Care Leavers, submitting:

*A further group requiring attention are Care Leavers, which is a special needs category used by the Australian Government to cover Forgotten Australians and Former Child Migrants. This group can also include the Stolen Generations. All three groups were impacted negatively by government policies as children and are reported to consist of over 500,000 people across Australia. The trauma these individuals have experienced bring lifelong implications and often create fear and distrust of aged care. Unfortunately, the current funding models of residential aged care and community-based support can limit services' ability to provide appropriate responses, particularly around choices in staffing. This can act as a barrier to providing care that does not re-traumatise Care Leavers.*⁹²⁴

Recommendations made by the Healing Foundation to better cater for Care Leavers can be found in section 9.9.1.

9.9.4 LGBTIQ+

Submitters to the inquiry who commented on the aged care needs of the LGBTIQ+ community commented that despite efforts to ensure diversity in the delivery of aged care, there were still gaps.⁹²⁵

The RANZCP submitted that, at present:

*...there are limited appropriate care options for older people from...Lesbian, Gay, Trans and Gender Diverse, and Intersex (LGBTI) peoples in Queensland. The Australian Government's Diversity Framework seeks to embed diversity in the design and delivery of aged care. However, our members have reported that there is still a lack of sensitivity to the diverse needs of older Queenslanders in the delivery of aged care, particularly in RACFs.*⁹²⁶

Similarly, the Queensland branch of the AASW advised it continues to identify the lack of resources and infrastructure to operationalise the delivery of person-centred care in aged care settings.⁹²⁷

9.9.5 Other people with special needs

9.9.5.1 People with disabilities

Stakeholders commented that the current aged care system does not adequately support people with disabilities. Palliative Care Nurses Australia noted that:

People with disabilities are now living long enough to require aged care. This group often has very high care needs and aged care services are not currently equipped or staffed to provide

⁹²³ Public hearing transcript, Brisbane, 18 October 2019, p 4.

⁹²⁴ Submission 1288, p 11.

⁹²⁵ See, for example, submissions, 1207, 1288, 1297.

⁹²⁶ Submission 1207, attachment, p 3.

⁹²⁷ Submission 1288, p 11.

*optimum care for this group. The available aged care allied health services are insufficient to meet the needs of this population.*⁹²⁸

Mr Ian Landreth, CEO of Motor Neurone Disease Association of Queensland referred to the ‘systematic discrimination’ against MND sufferers, telling the committee:

*The National Disability Insurance Scheme provides for a client focused management and care plan, and equipment and support to facilitate that if you have a disability registered with the NDIS before your 65th birthday. However, if you are diagnosed after your 65th birthday the only financial funding available is through a My Aged Care grant, which is not designed to support a disability. It does not cover equipment or coordinated care planning. It is means tested and requires a co-contribution and, at its highest, is maybe only 30 per cent of the level of NDIS funding available to you if you had not just had your 65th birthday. The time it takes to be granted this funding is often longer than the client has to live. The only support that these over-65-year-old Queenslanders, their families and carers get is from organisations like ours, from fundraising, donations and bequests. These charities save Queensland Health millions of dollars a year and Queensland Health’s contribution has been zero.*⁹²⁹

Ms Linda Mungomery similarly submitted that the aged care system supports a lower level of care than the NDIS for persons in equivalent dependent states, stating ‘If you transition into old age with a NDIS package you have a major advantage to continue person-centred care with more control’.⁹³⁰

Linda Mungomery suggested that, in relation to home care packages, greater flexibility is needed similar to that provided by the NDIS. She submitted:

*Other models of care very much depend on the support of family and friends and their involvement. A flexible system would allow for this, but the current packages do not. If family could manage the package, as is the case with the NDIS, the dollars can go much further to proving care. I found that less than 40 % of packages were spent on care.*⁹³¹

Queensland PHNs advised that people aged under 65 needing home care via the Queensland Community Care program must now have an NDIS assessment first, therefore slowing down the access time to home care support services and increasing the risk of avoidable hospitalisations. Queensland PHNs also suggested that the disconnect between disability and aged care services puts people at risk.⁹³²

9.9.5.2 Dementia and mental health issues

Stakeholders identified gaps in the provision of aged care for people with dementia and mental health issues, including equity of access, quality and safety of services, dementia education and the current models of care.

Dementia Australia identified inequitable access to aged care services as a significant systemic challenge they believe the aged care system faces in meeting the current and future needs of people impacted by dementia.⁹³³

In terms of equity of access for those living at home, Dementia Australia advised that the shortage in appropriate-level packages and targeted supports:

⁹²⁸ Submission 1305, p 5.

⁹²⁹ Public hearing transcript, Brisbane, 13 September 2019, p 2.

⁹³⁰ Submission 1370, p 1.

⁹³¹ Submission 1370, p 3.

⁹³² Submission 1301, p 5.

⁹³³ Submission 1621, p 6.

...is having a significant impact on the ability of people with dementia, their families and carers to remain at home, and potentially increasing the number of acute health interventions required.

Even once an aged care package has become available, people with dementia are no more confident in navigating the system to ensure they receive the right support at any given time – and given the progressive nature of dementia, support needs can often change.⁹³⁴

In support of home care, the RANZCP advised that home based mental health treatment for older people can reduce entry to hospital and residential care, improve quality of life for older people, and reduce healthcare costs. If home-based mental health treatment is not provided, they stated:

Both reduction in access to appropriate mental health care, and absence of appropriate community alternatives to residential care, increase the risk of inappropriate entry to residential aged care. Furthermore, people with mental illness appear to then have an increased risk of entry to residential care facilities that have poorer standards of care provision (RANZCP, 2015).⁹³⁵

To assist people with dementia in accessing aged care, Dementia Australia recommended that navigational support that is approachable for people living with dementia (e.g face-to-face support, or a helpline service where staff are knowledgeable on the topic of dementia) should be a priority and would enable people with dementia, their families and carers to receive support that encourages reablement and suits the unique needs of someone living with dementia.⁹³⁶ Dementia Australia recommended:

Queensland Health should have suitable dementia specific guidance on how to access services. This information should be easily accessible from the moment of diagnosis. Adopting effective system navigators – which are user friendly for people living with dementia – will also assist people with dementia to access the services they need.

Churches of Christ addressed the availability of dementia-specific places in RACFs, stating:

Older people with dementia or other conditions particularly mental health issues, which cause severe behavioural symptoms provide significant challenges for residential aged care settings, with significant risk to other frail elderly residents and staff. The Australian Government has committed to establish at least one small unit (c. 10 beds) in each Primary Health Network, based on current and projected demographics. 10 beds will be insufficient to assess and accommodate people experiencing such severe symptoms.⁹³⁷

The AASW Queensland Branch noted the importance of the SBRT, because without such support ‘older people can be sent to hospital and often cannot return to their home in aged care as facilities are unable to manage their behaviours’.⁹³⁸

Some submitters recommended considering different models of care to assist those living with dementia. For example, National Seniors Australia referred to examples in Australia and overseas in the Netherlands and Denmark of different service delivery models for clients with dementia. As an example, they referred to a dementia village being built in Tasmania for people suffering with dementia, which will include 15 tailored homes, with a supermarket, café and cinema and gardens. National Seniors Australia advised that the village is based on the model used by the De Hogeweyk

⁹³⁴ Submission 1621, p 7.

⁹³⁵ Submission 1207, attachment, p 2.

⁹³⁶ Submission 1621, p 7.

⁹³⁷ Submission 1281, pp 3-4.

⁹³⁸ Submission 1288, p 7.

village in the Netherlands.⁹³⁹ CentaCareCQ also suggested that models of care developed overseas for people with dementia should be considered.⁹⁴⁰

LASA referred to new models of aged care that are emerging, such as the dementia villages, but also referred to a shift away from the larger institutional setting to smaller villas in groups of six to eight residents.⁹⁴¹

Dr Lilantha Basnayake argued that the current model of care for residents with dementia in nursing homes, particularly residents who have behavioural and psychological symptoms of dementia and need a lot of assistance, is not satisfactory to manage those patients. He advised 'They are pretty much in a locked environment with that disease, I think primarily because of the resources that are available to nursing homes to manage those complicated patients'.⁹⁴² Dr Basnayake recommended that RACFs should better simulate their home environment along with specialist input to manage those patients.⁹⁴³

Dementia Australia also identified education as a systemic challenge facing the aged care sector. Dementia Australia recommended that 'A concerted focus on workforce skills and sustainability is a vital component of the aged care system as a whole, and a focus on mandatory dementia education should be a key consideration for the future of aged care in Queensland'.⁹⁴⁴ Further discussion on the importance of training in the areas of dementia and mental health is discussed in section 9.8.2

HammondCare, however, observed that while improving service provider knowledge and understanding of dementia will improve the support and care available to clients and residents living with dementia, the needs of people with dementia vary greatly and it is unreasonable to expect that all services can adequately serve all people living with dementia. HammondCare advised it supports specialisation among aged care providers to better service the individual profiles of people living with dementia, stating:

In order to better serve the growing needs of Queenslanders living with dementia and meet future demands for aged care, HammondCare calls for an increase in the number of aged care services specialising in the needs of people with dementia. Dementia-specific home care services promote choice, independence and social inclusion for people living with dementia, while purpose built residential care facilities foster greater resident autonomy and quality of life (Dyer et al., 2018). HammondCare's experience of specialisation demonstrates that a clear focus enables services to develop expertise and models of care better aimed at responding to the individual needs of people living with dementia. We are mindful of the important role the physical and social environment can play in supporting dignity, maximising independence and promoting feelings of comfort and security in our residents. As such, HammondCare's residential care services proudly champion an evidence informed domestic model of care (Afendulis et al. 2016; Ausserhofer et al. 2006; Dyer et al. 2018).⁹⁴⁵

For those people living with dementia whose goal is to remain living at home for as long as possible, HammondCare expressed its support for additional funding for cottage respite services:

...a model consistently favoured by care recipients and their carers that is well suited to providing tailored care to individuals living with dementia (Carers Australia 2018; Poulos and Birch 2016). Cottage respite provides overnight respite care out of converted family homes in the community

⁹³⁹ Submission 1309, p 6.

⁹⁴⁰ Submission 1297, p 7.

⁹⁴¹ Submission 1283, p 5.

⁹⁴² Public hearing transcript, Toowoomba, 17 May 2019, p 2.

⁹⁴³ Public hearing transcript, Toowoomba, 17 May 2019, p 2.

⁹⁴⁴ Submission 1621, p 5.

⁹⁴⁵ Submission 1261, p 3.

*or cottage-style facilities on state government land, offering flexible services within a more familiar and home-like environment. This small-scale and highly adaptable care setting is particularly well suited to people living with dementia. HammondCare's experience with cottage respite has been overwhelmingly positive; the service suits many carers who prefer to have one or two nights of respite more regularly instead of blocks, and is commonly used multiple times by the same consumers, promoting continuity of care and relationships of trust.*⁹⁴⁶

Dementia Australia also raised the issue of quality and safety as a systemic challenge, stating:

*... the quality and safety mechanisms in dementia-specific care are neither consistent nor effective across the aged care system. There is a spectrum of issues around quality in aged care that ranges from poor quality to criminal negligence and abuse.*⁹⁴⁷

To address the issue of quality, Dementia Australia submitted:

*Essential drivers of quality improvement will include improved regulation and publicly reported quality indicators – which will help encourage transparency amongst providers on the services they offer. Ultimately, people with dementia, their families and carers want to have clear information about the quality of services being offered and the impact of those services on quality of life. Encouraging transparency from providers will not only allow consumers to make better informed decisions when it comes to their care, but should also have a positive impact on the provision of high quality care amongst providers.*⁹⁴⁸

Ms Janet Corcoran told of her experience with dementia patients when visiting her husband in a Cairns nursing home:

We have two floors—the first and the ground floor—which is divided into six or four different wards. They do not have a dementia protection area. I believe that some of these patients are good escape artists. One in particular I have been picking up off a main road, because I have been out around at tea time when she likes to go for a walk looking for her husband. I get her in. A report may not be documented, but they have moved her. A couple of weeks back, a 95-year-old strong lady went into a room and pushed a patient. She cracked her head on the back. Fortunately, she bled on the outside of her skull and not the inside.

*...I am concerned that someone is going to end up in a more serious condition and it is going to be fatal. They are allowed to walk or do whatever they want to. Some are very aggressive. I have been hit by one or two as I have walked past and I am concerned for safety. The person who was hit by this elderly lady had only just come in. She was put in there for care and safety. I think we need to protect the ones with dementia and the residents who are able and do not have dementia. I really feel that something has to be done before there is a nasty accident.*⁹⁴⁹

On the issue of mental illness, the LCAQD advised they are seeing increasing demand from people who are ageing who also have longstanding and persistent mental illnesses.⁹⁵⁰

RANZCP commented on the importance of access to mental health care in RACFs to help older people maintain good mental health and wellbeing. The RANZCP recommended the Queensland government advocate the Australian Government to:

⁹⁴⁶ Submission 1261, p 4.

⁹⁴⁷ Submission 1621, p 7.

⁹⁴⁸ Submission 1621, p 7.

⁹⁴⁹ Public hearing transcript, Cairns, 27 May 2019, pp 24-25.

⁹⁵⁰ Submission 1277, p 4.

- ensure that people living in RACFs have full access to the Medicare Benefits Scheme, in particular the mental health items⁹⁵¹
- mandate a formal aged care accreditation standard requiring all aged care providers to make mental health care and assessment by qualified professionals (e.g. psychologists, GPs, psychiatrists) available to people residing in RACFs
- develop best practice guidelines/quality standards to improve the mental health and wellbeing of people living in RACFs, such as the quality standard used in the UK, the 'National Institute for Health and Care Excellence – Mental wellbeing of older people in care homes'.⁹⁵²

9.9.5.3 Young people in residential aged care facilities

The RANZCP referred to the impacts of living in a RACF on young people:

*Placement of young people in RACFs is highly inappropriate for a multitude of reasons. These facilities are designed for an older aged cohort who are coming to the end of their life span. Loneliness, boredom and grief characterises many young people's experiences of RACFs. Despite the federal government's newly introduced action plan and the efforts of the National Disability Insurance Agency, we call upon the Queensland government to work with these stakeholders to prioritise the creation of more appropriate specialised housing, in consultation with this cohort, their families and carers.*⁹⁵³

The Public Advocate also raised the issue of young people in RACFs and referred to the Australian Government's Younger People in Residential Aged Care – Action Plan, submitting:

While the plan acknowledges that 'younger people with disability often have complex health needs and the difficulty in accessing appropriate health supports in other settings is one of the main reasons younger people go to live in aged care', the focus of the national plan is on appropriate accommodation and disability supports only, rather than health care needs.

*This rate of avoidable deaths will potentially escalate if young people residing in residential aged care facilities are transitioned into accommodation within the general community without a commitment from either the Queensland or Australian Governments to also providing the necessary health supports to manage their various health conditions.*⁹⁵⁴

The Public Advocate recommended that the Queensland Government:

- ensure that individual health care plans are developed for Queenslanders with disability in care, especially those transitioning from residential aged care and Queensland Health facilities to community living arrangements;
- require that those plans are reviewed and updated annually;
- ensure that the person's health care needs, as identified in their plans, inform their disability service providers of the supports required to adequately meet their health care needs and inform their NDIS plans;
- seek to clarify and finally settle with the Australian Government the funding issues associated with the provision of necessary health supports for people with disability seeking to transition from residential aged care facilities (and other health and disability facilities,) so that they can live healthy lives in the community.⁹⁵⁵

⁹⁵¹ Submission 1207, attachment, p 7.

⁹⁵² Submission 1207, attachment, p 7.

⁹⁵³ Submission 1207, attachment, p 4.

⁹⁵⁴ Submission 1208, p 12.

⁹⁵⁵ Submission 1208, p 13.

Churches of Christ explained the care they provide to young people:

*We experience challenges for younger severely disabled people requiring residential care and unable to find age appropriate group settings to meet their needs. We seek to accommodate such people where we believe we can meet their needs. However we are very conscious that they are joining a community of very frail, elderly people who are generally in the last months or years of their life and that this is not necessarily the setting of choice for younger people with a disability.*⁹⁵⁶

The Royal Commission strongly opposed the use of RACFs for young people, stating:

*In their evidence to the Royal Commission, Australian Government officials acknowledged that it is inappropriate for younger people to live in aged care settings.*⁹⁵⁷

...

*Over the 2017–18 financial year, a total of 2187 younger people entered residential aged care. That figure equates to 42 younger people, on average, entering residential aged care every week.*⁹⁵⁸

...

*The presence of younger people in residential aged care is a symptom of the failures of other systems, and too often residential aged care is offered as a default response.*⁹⁵⁹

...

*The Royal Commission heard multiple accounts from younger people who have been, or remain, in residential aged care. They spoke of the social isolation, neglect, loss of function, sense of hopelessness and grief associated with their time in aged care.*⁹⁶⁰

Committee comment

Aged care should be provided in a way that is respectful of the diverse needs of older people with special needs. This includes the needs of older people who are suffering from mental health issues; are from culturally and linguistically diverse backgrounds; are from Aboriginal and Torres Strait Islander communities; or are from LGBTIQ+ communities.

Clients in the aged care system who have dementia, and their representatives, have a more difficult journey than most. Given the prevalence of dementia and the high proportion of clients with dementia in residential aged care, it is timely that all aged care workers undertake basic dementia care training. Staff cannot be expected to understand dementia care if they have not received the appropriate training.

⁹⁵⁶ Submission 1281, p 3.

⁹⁵⁷ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 233, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁹⁵⁸ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 234, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁹⁵⁹ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 236, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁹⁶⁰ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 239, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

Young people do not belong in residential aged care facilities, however are ending up in these facilities as there are a lack of alternatives for supporting young people with health issues. Residing in a residential aged care facility for a young person has been described as an ‘isolating and daunting experience’.⁹⁶¹ The Royal Commission in its Interim Report, identified the need for urgent action to ‘to stop the flow of younger people with disability going into aged care, and expediting the process of getting those younger people who are already in aged care out’.⁹⁶²

Recommendation 24 Training and resources about special needs clients

The committee recommends that the Australian Government consider requiring aged care providers to ensure all aged care staff have access to training and resources to promote awareness and understanding of the special needs of clients who are from groups with special needs such as clients:

- suffering from mental health issues
- from culturally and linguistically diverse backgrounds
- from Aboriginal and Torres Strait Islander communities, and
- from LGBTIQ+ communities.

Recommendation 25 Training opportunities for Aboriginal and Torres Strait Islander people

The committee recommends that the Australian Government fund trainee positions for Aboriginal and Torres Strait Islander people to work in roles providing aged care and health care for Aboriginal and Torres Strait Islander people.

Recommendation 26 Mandatory dementia care training for all aged care workers

The committee recommends that the Australian Government mandate that accredited dementia care training is undertaken by all aged care workers.

Recommendation 27 Reducing the number of young people in aged care facilities

The committee recommends that the Australian Government act immediately to reduce the number of young people with health issues entering residential aged care facilities, and to provide them alternative housing arrangements that meet their requirements.

⁹⁶¹ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 4, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

⁹⁶² Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 10, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

10 Quality of aged care

As part of reforms to the aged care system, the Australian Government is developing what it calls ‘an end-to-end, market-based system with the sector where the consumer drives quality’.⁹⁶³ This includes a Single Aged Care Quality Framework (single quality framework) with:

- a single set of quality standards for all aged care services called the Aged Care Quality Standards (see section 11.1 on the ACQSC)
- quality assessment arrangements for assessing provider performance against quality standards
- a single Charter of Aged Care Rights for all aged care recipients, and
- publication of information about quality to help consumers choose aged care and services (see section 5.1 on My Aged Care).⁹⁶⁴

10.1 Charter of Aged Care Rights

The current Charter of Aged Care rights began on 1 July 2019, and is designed to protect the rights of people receiving aged care. The Charter applies to consumers once they start receiving Australian Government funded aged care, including:

- residential care
- home care packages
- flexible care
- services provided under the Commonwealth Home Support Programme and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program.⁹⁶⁵

The Charter provides the following rights:

1. safe and high quality care and services
2. be treated with dignity and respect
3. have my identity, culture and diversity valued and supported
4. live without abuse and neglect
5. be informed about my care and services in a way I understand
6. access all information about myself, including information about my rights, care and services
7. have control over and make choices about my care, and personal and social life, including where the choices involve personal risk

⁹⁶³ Australian Government, Department of Health, Single Aged Care Quality Framework - Options for assessing performance against aged care quality standards, <https://consultations.health.gov.au/aged-care-access-and-quality-acaq/single-quality-framework-assessing-performance/>.

⁹⁶⁴ Australian Government, Department of Health, Single Aged Care Quality Framework - Options for assessing performance against aged care quality standards, <https://consultations.health.gov.au/aged-care-access-and-quality-acaq/single-quality-framework-assessing-performance/>.

⁹⁶⁵ Australian Government, Department of Health, Delivering quality aged care services, <https://www.health.gov.au/health-topics/aged-care/providing-aged-care-services/delivering-quality-aged-care-services>.

8. have control over, and make decisions about, the personal aspects of my daily life, financial affairs and possessions
9. my independence
10. be listened to and understood
11. have a person of my choice, including an aged care advocate, support me or speak on my behalf
12. complain free from reprisal, and to have my complaints dealt with fairly and promptly
13. personal privacy and to have my personal information protected
14. exercise my rights without it adversely affecting the way I am treated.⁹⁶⁶

10.2 National Aged Care Mandatory Quality Indicator Program

The Australian Government has also introduced the National Aged Care Mandatory Quality Indicator Program, which began on 1 July 2019. According to the Department of Health's website 'Quality indicators measure aspects of service provision which contribute to the quality of care and services given by the provider, and to care recipients' quality of life and experiences'.⁹⁶⁷

The objectives of the National Aged Care Mandatory Quality Indicator Program are:

- for providers to have robust, valid data to measure and monitor their performance and support continuous quality improvement, and
- over time, to give consumers transparent, comparable information about quality in aged care to aid decision making.⁹⁶⁸

This program is mandatory for all Commonwealth subsidised residential aged care services. Each service must collect and provide quality indicator data to the Department of Health against the following quality indicators:

- pressure injuries
- use of physical restraint
- unplanned weight loss.⁹⁶⁹

10.3 Serious Incident Response Scheme

A serious incident response scheme (SIRS) was initially proposed by the Carnell-Paterson Review in 2017. The Australian Government is proposing to reduce the risk of abuse and better respond to serious incidents in government-subsidised residential aged care via such a scheme. According to the

⁹⁶⁶ Australian Government, Aged Care Quality and Safety Commission, Charter of Aged Care Rights, <https://www.agedcarequality.gov.au/consumers/consumer-rights>.

⁹⁶⁷ Australian Government, Department of Health, Delivering, National Aged Care Mandatory Quality Indicator Program, <https://www.health.gov.au/initiatives-and-programs/national-aged-care-mandatory-quality-indicator-program>.

⁹⁶⁸ Australian Government, Department of Health, Delivering, National Aged Care Mandatory Quality Indicator Program, <https://www.health.gov.au/initiatives-and-programs/national-aged-care-mandatory-quality-indicator-program>.

⁹⁶⁹ Australian Government, Department of Health, Delivering, National Aged Care Mandatory Quality Indicator Program, <https://www.health.gov.au/initiatives-and-programs/national-aged-care-mandatory-quality-indicator-program>.

Department of Health, 'SIRS will build the ability of providers to better manage incidents if they occur and make sure care recipients are supported'.⁹⁷⁰

The SIRS approach is proposed to help aged care service providers:

- reduce the risk of abuse and neglect in aged care
- respond to and manage serious incidents that occur in residential aged care
- support care recipients affected by a serious incident.⁹⁷¹

The Department of Health states that SIRS aims to:

- strengthen governance in aged care to reduce the risk of abuse and neglect
- build providers' skills so they can better respond to serious incidents
- ensure people receiving aged care have the support they need.⁹⁷²

In the 2019–20 Budget, the Australian Government provided \$1.5 million to prepare for introducing SIRS, including:

- public consultation on the details of SIRS
- a study for a possible register of staff for the aged care sector
- research into incidents between aged care residents (currently not reportable) to help redefine what serious incidents are.⁹⁷³

The public consultation closed on 11 October 2019.⁹⁷⁴

10.4 Information on quality of services

According to the Department of Health, the Australian Government has included the following aged care service quality information on the My Aged Care website to assist consumers to make informed decisions about their care and services:

- improvements to the home care packages service finder, enabling providers to advertise detailed information about their costs and the addition of search fields such as: religion, language, special needs and specialised services
- a 'Non-Compliance Checker' to allow consumers to more easily search for current and archived compliance action taken against residential services and home care package providers
- information about how to find quality services, questions to ask providers when choosing an aged care home, and how consumers' rights are protected
- information about a residential aged care service's accreditation status with improved links to the Aged Care Quality and Safety Commission's accreditation audit reports and consumer experience reports, where available

⁹⁷⁰ Australian Government, Department of Health, Serious Incident Response Scheme (SIRS), <https://www.health.gov.au/initiatives-and-programs/serious-incident-response-scheme-sirs>.

⁹⁷¹ Australian Government, Department of Health, Serious Incident Response Scheme (SIRS), <https://www.health.gov.au/initiatives-and-programs/serious-incident-response-scheme-sirs>.

⁹⁷² Australian Government, Department of Health, Serious Incident Response Scheme (SIRS), <https://www.health.gov.au/initiatives-and-programs/serious-incident-response-scheme-sirs>.

⁹⁷³ Australian Government, Department of Health, Serious Incident Response Scheme (SIRS), <https://www.health.gov.au/initiatives-and-programs/serious-incident-response-scheme-sirs>.

⁹⁷⁴ Australian Government, Department of Health, Serious Incident Response Scheme (SIRS), <https://www.health.gov.au/initiatives-and-programs/serious-incident-response-scheme-sirs>.

- an icon in the 'Find a provider tool' identifying a provider's participation in the National Aged Care Mandatory Quality Indicator Program for residential aged care providers, and
- updates which aim to make it easier for consumers to find relevant information about complaints, advocacy and quality.⁹⁷⁵

⁹⁷⁵ Australian Government, Department of Health, Delivering quality aged care services, <https://www.health.gov.au/health-topics/aged-care/providing-aged-care-services/delivering-quality-aged-care-services>.

11 The regulation of aged care

The Aged Care Quality and Safety Commission (ACQSC) and the Department of Health each share responsibilities for the regulation and monitoring of Australian aged care services. In 2019 and 2020, the roles and functions of these entities were altered. Their respective roles and functions together with a description of how aged care is regulated, are outlined in the following sections.

To a lesser extent, in Queensland, the OHO provides an oversight mechanism of aged care services as it deals with some aged care sector complaints. Similarly, the Coroner may investigate an aged care death where it relates to the quality of care provided. This chapter also includes discussion of the operation of these organisations in relation to the regulation of aged care.

A number of stakeholders contacted the committee about the regulation of aged care. Their views as well as comments from the Royal Commission about the regulation of aged care services are also included in this chapter.

11.1 Aged Care Quality and Safety Commission

The regulation and monitoring of Australian aged care services was previously the responsibility of both the Australian Aged Care Quality Agency and the Aged Care Complaints Commissioner.

The Carnell-Paterson report, which was commissioned as a result of the report on the Oakden Older Persons Mental Health Service, recommended that a Commission be established to centralise accreditation, compliance and complaints handling functions in one body. This recommendation led to the establishment of the independent statutory agency, the ACQSC, from 1 January 2019. The ACQSC replaced the functions of the Australian Aged Care Quality Agency and the Aged Care Complaints Commissioner.⁹⁷⁶

The ACQSC was formally established under the *Aged Care Quality and Safety Commission Act 2018* (Cth) (the ACQSC Act) and the *Aged Care Quality and Safety Commission Rules 2018* (Cth) (the Rules). The ACQSC Act and Rules apply to both approved providers of residential aged care or home-care services, and Commonwealth-funded aged care service providers. The ACQSC Act also establishes the Aged Care Quality and Safety Advisory Council and provides for its functions, membership, procedures, reporting and planning, information sharing and entry and search powers.

In May 2019 the ACQSC was responsible for assisting the Aged Care Quality and Safety Commissioner (Commissioner) with functions that included:

- *protecting and enhancing the safety, health, well-being and quality of life of aged care consumers*
- *promoting the provision of quality care and services by approved providers of aged care services and service providers of Commonwealth-funded aged care services*
- *consumer engagement*
- *complaints handling*
- *regulatory responsibilities (accreditation, quality assessment, review and compliance monitoring)*

⁹⁷⁶ Parliament of Australia, Parliamentary Library, Bills Digest No. 49, 2019–20, Aged Care Legislation Amendment (New Commissioner Functions) Bill 2019, https://parlinfo.aph.gov.au/parlInfo/download/legislation/billsdgs/7019716/upload_binary/7019716.pdf.

- *providing information and education.*⁹⁷⁷

In late 2019, the Australian Parliament passed the *Aged Care Legislation Amendment (New Commissioner Functions) Act 2019* (Cth) to transfer additional aged care regulatory functions to the Aged Care Quality and Safety Commissioner from the Department of Health. These new functions include approving providers of aged care, and monitoring and enforcing their compliance with their aged care responsibilities.⁹⁷⁸ The explanatory notes specified:

*The Aged Care Quality and Safety Commission (Commission) will be the primary point of contact for providers and consumers in relation to quality of care and regulation. Centralising these regulatory functions and powers within a single regulator will address the fragmentation and silos identified in the Review of National Aged Care Quality Regulatory Processes.*⁹⁷⁹

On 1 January 2020, in accordance with the *Aged Care Legislation Amendment (New Commissioner Functions) Act 2019* (Cth), new responsibilities were transferred from the Department of Health to the ACQSC, including:

- *aged care compliance and enforcement actions*
- *compulsory reporting of assaults*
- *prudential compliance operations*
- *approving all residential and home care providers*
- *home care compliance and investigations.*⁹⁸⁰

The functions listed above include independently accrediting, assessing and monitoring aged care services subsidised by the Australian Government.⁹⁸¹

11.1.1 Quality standards

In 2018, as part of the recent reforms to the aged care system, the Australian Government endorsed a new aged care quality framework. The framework includes:

- *a single set of quality standards for all aged care services called the Aged Care Quality Standards;*
- *improved quality assessment arrangements for assessing provider performance against quality standards;*
- *a single Charter of Aged Care Rights for all aged care recipients; and,*
- *publication of improved information about quality to help consumers choose aged care and services.*⁹⁸²

⁹⁷⁷ <https://www.agedcarequality.gov.au/resources/key-changes-providers-aged-care-quality-and-safety-commission-legislation>; Aged Care Quality and Safety Commission, public briefing transcript, Brisbane, 13 May 2019, p 3.

⁹⁷⁸ Aged Care Legislation Amendment (New Commissioner Functions) Bill 2019, Explanatory Memorandum, p 1.

⁹⁷⁹ Aged Care Legislation Amendment (New Commissioner Functions) Bill 2019, Explanatory Memorandum, p 1.

⁹⁸⁰ Australian Government, Department of Health, <https://www.health.gov.au/news/aged-care-quality-and-safety-commission-role-expands>.

⁹⁸¹ Australian Government, Aged Care Quality and Safety Commission, *Annual Report 2018-19*, p 21.

⁹⁸² Commonwealth Department of Health, Single quality framework: focus on consumers, <https://agedcare.health.gov.au/quality/single-quality-framework-focus-on-consumers>.

According to the Annual Report of the Australian Aged Care Quality Agency, these new standards focus on ‘quality outcomes for consumers rather than just provider processes’.⁹⁸³ The goal of the new standards is to make it ‘easier for consumers, their families, carers and representatives to understand what they can expect from a service’ and to ‘make regulation simpler for providers working across multiple aged care services’.⁹⁸⁴

The new Aged Care Quality Standards comprise:

- *consumer dignity and choice*
- *ongoing assessment and planning with consumers*
- *personal care and clinical care*
- *services and supports for daily living*
- *organisation’s service environment*
- *feedback and complaints*
- *human resources*
- *organisational governance*.⁹⁸⁵

Each of the Aged Care Quality Standards is expressed in three ways:

- *a statement of outcome for the consumer*
- *a statement of expectation for the organisation*
- *organisational requirements to demonstrate that the standard has been met*.⁹⁸⁶

The new Aged Care Quality Standards now apply to all aged care services including residential care, home care, flexible care and services under the CHSP.⁹⁸⁷ Transition to the new standards commenced from July 2018 and approved providers have been assessed against them since July 2019.⁹⁸⁸

11.1.2 Regulation by ACQSC

According to its Annual Report, the ACQSC operates a risk based regulatory program to facilitate a responsive regulatory based approach which enables it to ‘respond appropriately to instances of failure’.⁹⁸⁹ It does this through:

⁹⁸³ Aged Care Quality Agency, Annual Report 2017-18, p 12, https://www.agedcarequality.gov.au/sites/default/files/media/aacqa_annual_report_2017-18.pdf.

⁹⁸⁴ Aged Care Quality Agency, Annual Report 2017-18, p 12, https://www.agedcarequality.gov.au/sites/default/files/media/aacqa_annual_report_2017-18.pdf.

⁹⁸⁵ Australian Government, Aged Care Quality and Safety Commission, Guidance and Resources for Providers to support the Aged Care Quality Standards, <https://www.agedcarequality.gov.au/sites/default/files/media/Full%20Standards%20Guidance%201-8%20Updated%20180119.pdf>.

⁹⁸⁶ Australian Government, Aged Care Quality and Safety Commission, Guidance and Resources for Providers to support the Aged Care Quality Standards, <https://www.agedcarequality.gov.au/sites/default/files/media/Full%20Standards%20Guidance%201-8%20Updated%20180119.pdf>.

⁹⁸⁷ Australian Government, Department of Health, Single set of quality standards – the Aged Care Quality Standards, <https://www.agedcarequality.gov.au/providers/standards>.

⁹⁸⁸ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 22.

⁹⁸⁹ Australian Government, Aged Care Quality and Safety Commission, *Annual Report 2018-19*, p 16, <https://www.agedcarequality.gov.au/media/86747>.

- *the accreditation of residential aged care services and flexible care services through which short term restorative care is provided in a residential care setting against the Accreditation Standards*
- *quality review of home services against the Home Care Standards*
- *quality review of National Aboriginal and Torres Strait Islander Flexible Aged Care Program services against the Quality Program*
- *monitoring the quality of care and services provided by aged care services.*⁹⁹⁰

11.1.2.1 Accreditation and quality reviews

The Department of Health advised the ACQSC is responsible for the provision of quality assurance and that it undertakes quality reviews and accreditation processes:

*... in accordance with the Australian Aged Care Quality and Safety Commission Rules 2018. Provider performance is measured against the relevant standards set out in the Quality of Care Principles made under the Aged Care Act.*⁹⁹¹

Aged care service providers, subsidised by the Australian Government, are required to meet the responsibilities and standards of care set out in the Aged Care Act. Residential care services must be accredited to receive Australian Government subsidies and are assessed through re-accreditation audits which generally occur once every three years. Following recommendations of the Carnell-Paterson Review, the Government replaced announced re-accreditation audits with unannounced re-accreditation audits from July 2018.⁹⁹²

Residential Aged Care Facilities are overseen via accreditation (including assessment contacts), site audits, accreditation decisions and review audits.⁹⁹³

Home care services and CHSP services are assessed through quality reviews that are conducted at least once every three years. The new assessment methodology adopted in July 2019, involves performance assessments using site audits, quality reviews and assessment contacts.⁹⁹⁴

11.1.2.2 Performance Assessments

A performance assessment consists of 'obtaining and evaluating evidence to determine performance against the Quality Standards'.⁹⁹⁵ These performance assessments are undertaken by registered quality assessors using site audits, quality reviews and assessment contacts.

Site audits are a comprehensive assessment of a service's performance against all of the Aged Care Quality Standards. Since 2018 they occur without notice to the provider.⁹⁹⁶

⁹⁹⁰ Australian Government, Aged Care Quality and Safety Commission, Annual Report 2018-19, p 21, <https://www.agedcarequality.gov.au/media/86747>.

⁹⁹¹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 20.

⁹⁹² Australian Government, Aged Care Quality and Safety Commission, Annual Report 2018-19, p 21, <https://www.agedcarequality.gov.au/media/86747>.

⁹⁹³ Australian Government, Aged Care Quality and Safety Commission, Annual Report 2018-19, p 24, <https://www.agedcarequality.gov.au/media/86747>.

⁹⁹⁴ Australian Government, Aged Care Quality and Safety Commission, Annual Report 2018-19, p 21, <https://www.agedcarequality.gov.au/media/86747>.

⁹⁹⁵ Australian Government, Aged Care Quality and Safety Commission, Annual Report 2018-19, p 22, <https://www.agedcarequality.gov.au/media/86747>.

⁹⁹⁶ Australian Government, Aged Care Quality and Safety Commission, Annual Report 2018-19, p 24, <https://www.agedcarequality.gov.au/media/86747>.

A review audit is a site visit by an assessment team to conduct a full audit of the performance of a residential care service against the Accreditation Standards. It may be conducted if the ACQSC considers that the approved provider of the service may not be complying with the Accreditation Standards.⁹⁹⁷

Assessment contacts are any form of contact between the ACQSC and an approved provider for one or more of the following purposes:

- *to assess the approved provider's performance in relation to the service, against the Accreditation Standards, Home Care Standards or Flexible Care Standards (as applicable)*
- *to assist the approved provider's process of continuous improvement in relation to the service*
- *for residential aged care services, to identify whether there is a need for a review audit of the service*
- *for home care services, to identify whether there is a need for a quality review of the service*
- *to give the approved provider additional information or education about the assessment process and requirements.*⁹⁹⁸

Quality reviews and assessment contacts are undertaken on home services to assess whether a provider delivers services in accordance with the new Aged Care Quality Standards.⁹⁹⁹

According to the ACQSC factsheet, following a performance assessment, the report prepared by the assessment team will outline the team's assessment of performance against the Quality Standards and will provide a (Met or Not Met) finding. The report will be given to the ACQSC and to the provider for a response.¹⁰⁰⁰

Since January 2020, performance reports that follow a site audit or a review audit completed have been published on the ACQSC website. This reporting will extend to 'performance reports developed following an assessment contact (performance assessment) or quality review' in July 2020.¹⁰⁰¹

11.1.3 Non-compliance with the Aged Care Quality Standards

According to the factsheet published on the ACQSC website, the amendments to the rules that were implemented to support the transition of the regulatory function to the ACQSC, will establish a regulatory framework with 'graduated and escalating responses to non-compliance'.¹⁰⁰²

⁹⁹⁷ Aged Care Quality Agency, Annual Report 2017-18, p 24, https://www.agedcarequality.gov.au/sites/default/files/media/aacqa_annual_report_2017-18.pdf.

⁹⁹⁸ Aged Care Quality Agency, Annual Report 2017-18, p 23, https://www.agedcarequality.gov.au/sites/default/files/media/aacqa_annual_report_2017-18.pdf.

⁹⁹⁹ Australian Government, Aged Care Quality and Safety Commission, Annual Report 2018-19, p 26, <https://www.agedcarequality.gov.au/media/86747>.

¹⁰⁰⁰ Australian Government Aged Care Quality and Safety Commission, *Key changes for providers from 1 January 2020: Aged Care Quality and Safety Commission Rules*, p 2, <https://www.agedcarequality.gov.au/sites/default/files/media/Fact%20sheet%20-%20changes%20to%20the%20Rules%20-%20external%20facing.pdf>.

¹⁰⁰¹ Australian Government Aged Care Quality and Safety Commission, *Key changes for providers from 1 January 2020: Aged Care Quality and Safety Commission Rules*, p 2, <https://www.agedcarequality.gov.au/sites/default/files/media/Fact%20sheet%20-%20changes%20to%20the%20Rules%20-%20external%20facing.pdf>.

¹⁰⁰² Australian Government Aged Care Quality and Safety Commission, *Key changes for providers from 1 January 2020: Aged Care Quality and Safety Commission Rules*, p 1, <https://www.agedcarequality.gov.au/sites/default/files/media/Fact%20sheet%20-%20changes%20to%20the%20Rules%20-%20external%20facing.pdf>.

Where there is non-compliance with the Quality Standards, the Commissioner may issue the provider of the service with a:

- *Direction to revise a Plan for Continuous Improvement (PCI)*
- *Non-Compliance Notice*
- *Notice to Remedy*
- *Notice of Decision to Impose Sanctions.*¹⁰⁰³

In cases where the risk is assessed as low or medium, the ACQSC may notify the provider of the non-compliance and encourage rectification or issue to the provider a Direction to revise the PCI for the service.¹⁰⁰⁴ If the ACQSC is not satisfied with the response of the provider it may escalate the regulatory action.¹⁰⁰⁵

In circumstances where the risk is assessed as high or severe, the ACQSC may issue a Non-Compliance Notice. A Non-Compliance Notice advises the provider of the non-compliance and gives them the opportunity to respond. If satisfied with the provider's response, the ACQSC may issue a Notice to Remedy. A Notice to Remedy requires the provider to remedy the non-compliance within a certain period.¹⁰⁰⁶

If the ACQSC is not satisfied with the provider's response to the Non-Compliance Notice or where there is immediate and severe risk, the Delegate may issue a Notice of Decision to Impose Sanctions.¹⁰⁰⁷

*A range of sanctions may be placed on providers depending on the problems identified. Sanctions usually mean a service provider must use an expert to help fix the problems as quickly as possible. A sanction may also mean that the service provider can't take on any new care recipients while the sanction is in place.*¹⁰⁰⁸

Where there is an immediate and severe risk to consumers, the Aged Care Act allows sanctions to be imposed without first issuing a Notice of Non-Compliance. This action is aimed at protecting current and future care recipients' health, welfare and interests, as well as returning the provider to compliance.¹⁰⁰⁹

When a service provider has received a Notice of Non-Compliance this is published on the Non-Compliance Checker section of the My Aged Care website.¹⁰¹⁰ Home care package service providers

¹⁰⁰³ Australian Government Aged Care Quality and Safety Commission, *Regulatory Bulletin, Issue No. 2019–4.1*, p 3, <https://www.agedcarequality.gov.au/regulatory-bulletin>.

¹⁰⁰⁴ Australian Government Aged Care Quality and Safety Commission, *Regulatory Bulletin, Issue No. 2019–4.1*, p 5, <https://www.agedcarequality.gov.au/regulatory-bulletin>.

¹⁰⁰⁵ Australian Government Aged Care Quality and Safety Commission, *Regulatory Bulletin, Issue No. 2019–4.1*, p 5, <https://www.agedcarequality.gov.au/regulatory-bulletin>.

¹⁰⁰⁶ Australian Government Aged Care Quality and Safety Commission, *Regulatory Bulletin, Issue No. 2019–4.1*, p 5, <https://www.agedcarequality.gov.au/regulatory-bulletin>.

¹⁰⁰⁷ Australian Government Aged Care Quality and Safety Commission, *Regulatory Bulletin, Issue No. 2019–4.1*, p 5, <https://www.agedcarequality.gov.au/regulatory-bulletin>.

¹⁰⁰⁸ Australian Government, My Aged Care, Notices of non-compliance and sanctions, <https://www.myagedcare.gov.au/notices-non-compliance-and-sanctions>.

¹⁰⁰⁹ Commonwealth Department of Health, correspondence dated 22 January 2019, attachment, p 21.

¹⁰¹⁰ Australian Government, My Aged Care, Non-Compliance Checker, <https://www.myagedcare.gov.au/non-compliance-checker>.

that have received a Notice of Non-Compliance are also published on the My Aged Care website and on the Home Care Package Finder web page.¹⁰¹¹

Recipients receiving care and services from a sanctioned service provider will be informed via letter about each problem and what the sanctions mean.¹⁰¹² The service provider is expected to arrange a meeting with care recipients, as well as family members, to explain the problems and how they will be remedied.¹⁰¹³

11.1.4 Numbers of Complaints

In its factsheet about resolving complaints, the ACQSC advises that a person who has a concern or complaint about a service provider may raise any concerns with the aged care service provider in the first instance.¹⁰¹⁴ If they are unable or uncomfortable doing this or if the provider is unable to resolve their concern, then the complainant can contact the ACQSC. Complaints may be open, confidential or anonymous. Any person can raise a complaint or concern with the ACQSC.¹⁰¹⁵

In 2018-19 the ACQSC received 7,828 complaints regarding aged care services across Australia,¹⁰¹⁶ this represents an increase of 34% from 5799 complaints received by the former Aged Care Complaints Commissioner in 2017-18 and a 43% increase from 4,711 complaints in 2016-17.¹⁰¹⁷

Of the 7828, complaints received in 2018-19, 5,748 complaints were about residential care, which accounted for 73 per cent of all complaints.¹⁰¹⁸ In 2018-19, 20 per cent of complaints were about home care packages (1,552) and six per cent were about CHSP (451) and there were also 77 complaints about Flexible Care.¹⁰¹⁹

The most common issues raised in complaints about residential aged care were about

- *medication administration and management (1,077),*
- *falls prevention and post-fall management (723),*
- *personnel number and sufficiency (715),*
- *personal and oral hygiene (683) and*

¹⁰¹¹ Australian Government, My Aged Care, My Aged Care Quick Reference Guide – Create Service Delivery Outlets and Add Service Information, <https://www.health.gov.au/resources/publications/my-aged-care-quick-reference-guide-create-service-delivery-outlets-and-add-service-information>.

¹⁰¹² Australian Government, My Aged Care, Notices of non-compliance and sanctions, <https://www.myagedcare.gov.au/notices-non-compliance-and-sanctions>.

¹⁰¹³ Australian Government, My Aged Care, Notices of non-compliance and sanctions, <https://www.myagedcare.gov.au/notices-non-compliance-and-sanctions>.

¹⁰¹⁴ Australian Government, Aged Care Quality and Safety Commission, Resolving concerns about aged care, https://www.agedcarequality.gov.au/sites/default/files/media/acqsc_resolving-concerns-factsheet_0.pdf.

¹⁰¹⁵ Australian Government, Aged Care Quality and Safety Commission, Resolving concerns about aged care, https://www.agedcarequality.gov.au/sites/default/files/media/acqsc_resolving-concerns-factsheet_0.pdf.

¹⁰¹⁶ Australian Government, Aged Care Quality and Safety Commission, Annual Report 2018-19, p 44, <https://www.agedcarequality.gov.au/media/86747>.

¹⁰¹⁷ Aged Care Complaints Commissioner, Annual Report 2017-18, p 20, https://www.agedcarequality.gov.au/sites/default/files/media/aacqa_annual_report_2017-18.pdf.

¹⁰¹⁸ Australian Government, Aged Care Quality and Safety Commission, Annual Report 2018-19, p 44, <https://www.agedcarequality.gov.au/media/86747>.

¹⁰¹⁹ Australian Government, Aged Care Quality and Safety Commission, Annual Report 2018-19, p 44, <https://www.agedcarequality.gov.au/media/86747>.

- *constipation and continence management (517).*¹⁰²⁰

The most common issues raised about home care packages and the Commonwealth Home Support Programme related to fees and charges.¹⁰²¹

11.1.5 The ACQSC complaints process

According to its website, the ACQSC assesses the issues raised in complaints and establishes the level of risk to the consumer.¹⁰²² It takes into consideration the safety, dignity and choice of the consumer and the quality of care and services being delivered.¹⁰²³ The ACQSC may attempt to resolve the complaint directly with the service provider or commence a formal complaint resolution process.

11.1.5.1 Resolution process

Where early resolution is not an option, the ACQSC may use a 'resolution process' involving one or more of the following approaches to resolve the issues in a complaint:

- *conciliation (helping the complainant and the service provider to discuss the issues and reach an agreement to resolve the concern. This may involve phone calls, discussions and meetings.)*
- *investigation (investigations can be simple, for example gathering information and discussing the issues with both parties; or they can be more complex, involving visits to the service, analysing records and conducting interviews.)*
- *service provider resolution (the ACQSC can ask the service provider to examine a complainant's concern within a specified timeframe. This may involve working with the complainant to achieve an outcome.)*
- *mediation (if the ACQSC is unable to achieve the outcome the complainant is seeking, the ACQSC suggests that the complainant and the service provider engage an independent mediator.)*¹⁰²⁴

11.1.5.2 Resolution outcomes

When a complaint is finalised, the ACQSC advises the complainant and the service provider of the outcome, the process the ACQSC followed, and the information used to come to their decision. The ACQSC advised, in its factsheet titled 'Resolving Concerns', that it may be able to achieve any of the following:

- agreement between the complainant and the service provider that the concerns have been addressed
- the ACQSC is satisfied that the service provider has addressed the issue

¹⁰²⁰ Australian Government, Aged Care Quality and Safety Commission, Annual Report 2018-19, p 44, <https://www.agedcarequality.gov.au/media/86747>.

¹⁰²¹ Australian Government, Aged Care Quality and Safety Commission, Annual Report 2018-19, p 45, <https://www.agedcarequality.gov.au/media/86747>.

¹⁰²² Australian Government, Aged Care Quality and Safety Commission, <https://www.agedcarequality.gov.au/making-complaint/complaints-process>.

¹⁰²³ Australian Government, Aged Care Quality and Safety Commission, <https://www.agedcarequality.gov.au/making-complaint/complaints-process>.

¹⁰²⁴ Australian Government, Aged Care Quality and Safety Commission, Resolving concerns about aged care, https://www.agedcarequality.gov.au/sites/default/files/media/acqsc_resolving-concerns-factsheet_0.pdf.

- regulatory action if the issue raised or information about a complaint is provided to the ACQSC's Quality Assessment and Monitoring Group to consider a regulatory response¹⁰²⁵
- issuing a direction to a service provider to make changes where the ACQSC believes the service provider is not meeting their responsibilities¹⁰²⁶
- referral for compliance action to the Department of Health if the ACQSC is concerned the service provider has not complied with or is not complying with their responsibilities, or they have failed to comply with the Commissioner's directions
- take no further action in situations such as the matter being subject to legal proceedings or a coronial inquiry, the issue is better dealt with by another organisation, if the circumstances do not warrant further action or if the person receiving care does not want the complaint to be examined.¹⁰²⁷

11.2 The Australian Department of Health

One of the responsibilities of the Department of Health is to administer the Aged Care Act and other related aged care laws. These laws set out the rules for government-funded aged care. Its functions include:

- managing the My Aged Care website and contact centre to help older people, their families and carers access government-funded aged care services
- processing applications from organisations to become approved aged care providers
- publishing guidance to help aged care providers understand the laws
- responding to reports of non-compliance
- improving policy through reforms and reviews to support high quality aged care.¹⁰²⁸

Aged care approval and compliance functions were the responsibility of the Department of Health up until the end of 2019. As mentioned above, those functions have now been transferred to the ACQSC.

These changes were designed to address the comment in the Carnell-Paterson Review that best-practice governance arrangements should separate the policy advice agency from the independent regulator.¹⁰²⁹

¹⁰²⁵ This is usually related to a service's performance against the Aged Care Quality Standards. Australian Government, Aged Care Quality and Safety Commission, *Resolving concerns about aged care*, https://www.agedcarequality.gov.au/sites/default/files/media/resolving_concerns_fact_sheet_jan_2020.pdf.

¹⁰²⁶ A direction requires the service provider to demonstrate how they have met or will meet their responsibilities under the Aged Care Act 197 or their funding agreement with the Australian Government. Australian Government, Aged Care Quality and Safety Commission, *Resolving concerns about aged care*, www.agedcarequality.gov.au/sites/default/files/media/resolving_concerns_fact_sheet_jan_2020.pdf.

¹⁰²⁷ Australian Government, Aged Care Quality and Safety Commission, *Resolving concerns about aged care*, www.agedcarequality.gov.au/sites/default/files/media/resolving_concerns_fact_sheet_jan_2020.pdf.

¹⁰²⁸ Australian Government, Department of Health, <https://www.health.gov.au/health-topics/aged-care/about-aged-care/what-were-doing-about-aged-care#administering-aged-care-laws>.

¹⁰²⁹ Parliament of Australia, Parliamentary Library, Bills Digest No. 49, 2019–20, Aged Care Legislation Amendment (New Commissioner Functions) Bill 2019, https://parlinfo.aph.gov.au/parlInfo/download/legislation/billsdgs/7019716/upload_binary/7019716.pdf.

11.2.1 Concerns about the regulation of aged care

The previous sections provided information about the regulation and monitoring of Australian aged care services. This section presents the views of both stakeholders who made submissions or gave evidence to the committee in relation to operation the regulatory regime.

11.2.2 Stakeholder views about regulation

A number of stakeholders to the Inquiry provided comments about the regulation and monitoring of Australian aged care services.

Ms Vera Somerwil from the National Seniors Australia Policy Advisory Group stated:

*There is no requirement for providers to show evidence that the money received from governments is used in the provision of individual care. Providers only need to meet the standards set out in the aged-care quality standards. With the increasing frailty of aged-care consumers, staff should have basic knowledge of how to look after people who have dementia, and I am afraid they do not.*¹⁰³⁰

Anglicare Southern Queensland submitted along similar lines:

*... the government should legislate a minimum high standard of aged care for everyone who is eligible for care regardless of their capacity to pay or where they live. This standard must be properly funded.*¹⁰³¹

Ms Anita Groos submitted that aged care needs to be more regulated and quality controlled by the government, including minimum staff to patient ratios, time out of the room for elderly patients and special provisions for various levels of dementia.¹⁰³²

PCQ argued that the 'Commonwealth government should develop models that improve quality rather than compliance'.¹⁰³³

The Public Advocate Ms Mary Burgess provided the following assessment in relation to the Aged Care Quality Standards and the aged care regulations:

*However, the recent changes to the Aged Care Quality Standards and the aged care regulations which commence this week amount to little more than tinkering with a system that still leaves aged-care residents without proper legal protections and the system essentially unaccountable. We need appropriate regulation so these practices can be used within a proper legal framework that nominates an appropriate and accountable decision-maker and provides for appropriate review reporting and the protection of rights. The model should also include guidance to ensure that, when these practices are necessary, the least restrictive option is used for the shortest time possible and that it is applied in accordance with best practice standards. These are all characteristics of a model of restrictive practices recommended by the Australian Law Reform Commission in its 2017 report Elder abuse—A national legal response.*¹⁰³⁴

Furthermore, the Queensland PHNs explained:

The new aged care quality standards place a greater emphasis on consumers and true consumer engagement. However the standards are at a minimum level of quality. Surveys of residents pre announcement of the Royal Commission into Aged Care saw results of 1 in 4 agreeing that the quality of care is good and having trust in the care.

¹⁰³⁰ Public hearing transcript, Brisbane, 13 September 2019, p 11.

¹⁰³¹ Submission 1229, p 6.

¹⁰³² Submission E688.

¹⁰³³ Submission 1891, p 51.

¹⁰³⁴ Public hearing transcript, Brisbane, 5 July 2019, p 30.

For in-home services, clinical governance is becoming more critical as we see an increase in the complexity of clients and examination of if the clinical standards go far enough.

System fragmentation and lack of coordination are known issues but the standards are not measuring how well providers work with GPs and allied health (this interface should be measured and barriers identified (e.g.: difficult to engage with primary care professionals)).¹⁰³⁵

Brisbane South PHN made the following recommendations in relation to the assessments of RACFs:

Aged care facility assessment should move from just a pass or fail process to more of a formative assessment process, and be based on quality care improvement. Complaints need to be regarded in a positive light as a means of quality improvement. (Change the culture of complaints from 'fear of retribution' to 'a normal and welcome part of customer service' COTA)

- The current quality assessment process has strengths in relation to assessing internal processes, safety, resident needs and the accommodation. However, relationship-centred aspects of care have typically not been well assessed and this is critical for understanding quality of life, not just quality of care. This includes assessing the quality of relationships between staff and residents, the sense of community residents experience and the level of home-like environment*
- A clear pathway for feedback on quality issues (beyond established medication management committees) is required in the aged care setting for those staff working at the facility and external providers*
- A clear process is required for visiting providers such as GPs to make a complaint about an aged care facility, where initial approaches to the aged care facility have not resolved the problem at hand. (The Aged Care Commissioner Complaints process is clear for residents and families/carers, but not for other care providers).¹⁰³⁶*

The Queensland Branch of the RANZCP was concerned that aged care services appeared to vary widely in terms of standard of care. They also submitted:

.... The RANZCP QLD Branch is disappointed the new standards do not go further to address the needs of a diverse Australian population or their mental health and related disorders. For instance, the standards do not introduce appropriate minimum staff to resident ratios, or stipulate staff training standards for IDD [intellectual and developmental disorders], behavioural management, mental health and related disorders, and LGBTI and CALD issues.

Under the new standards consumers can access accreditation reports about residential aged care providers, it would be useful for consumers to access assessment ratings at a glance, similar to those provided by the National Quality Framework for Early Childhood Education and Care. We suggest the inquiry refer to the progress of these new standards.¹⁰³⁷

The QNMU suggested that health service standards used in the hospital sector should also be used in the aged care sector:

While new aged care quality standards come into force on 1 July 2019, it is the view of the QNMU these standards, while improved, do not reflect the significant health care component within aged care services. We recommend the health service standards that have been well established for the hospital sector should also apply in the aged care sector in relation to health care services.¹⁰³⁸

¹⁰³⁵ Submission 1301, p 5.

¹⁰³⁶ Submission 1212, p 5.

¹⁰³⁷ Submission 1207, attachment, pp 5-6.

¹⁰³⁸ Submission 1213, p 14.

The Royal Commission was also critical of the regulatory regime:

*We have heard evidence which suggests that the regulatory regime that is intended to ensure safety and quality of services is unfit for purpose and does not adequately deter poor practices. Indeed, it often fails to detect them. When it does so, remedial action is frequently ineffective. The regulatory regime appears to do little to encourage better practice beyond a minimum standard. We were flabbergasted to hear that, until recently, it was routine practice for large sections of the reports of accreditation audits of services conducted by the Aged Care Quality and Safety Commission to be generated by computer assisted text. In other words, the same positive words prompted by computers were used over and over again. Computers cannot determine quality; only people can and should do that.*¹⁰³⁹

In addition to the statement that the regulatory regime had failed, the Royal Commission outlined some of the consequences of this failure.

The major quality and safety issues which have been brought to our attention during this Royal Commission are:

- *inadequate prevention and management of wounds, sometimes leading to septicaemia and death*
- *poor continence management—many aged care residences don't encourage toilet use or strictly ration continence pads, often leaving distressed residents sitting or lying in urine or faeces*
- *dreadful food, nutrition and hydration, and insufficient attention to oral health, leading to widespread malnutrition, excruciating dental and other pain, and secondary conditions*
- *a high incidence of assaults by staff on residents and by residents on other residents and on staff*
- *common use of physical restraint on residents, not so much for their safety or wellbeing but to make them easier to manage*
- *widespread overprescribing, often without clear consent, of drugs which sedate residents, rendering them drowsy and unresponsive to visiting family and removing their ability to interact with people*
- *patchy and fragmented palliative care for residents who are dying, creating unnecessary distress for both the dying person and their family.*

*It is shameful that such a list can be produced in 21st century Australia.*¹⁰⁴⁰

11.2.3 Issues with the accreditation process

In April 2019, the Senate Community Affairs References Committee reported on the effectiveness of the aged care quality assessment and accreditation framework and found that, '...accreditation auditors do not necessarily have a background in clinical care, and may not be best placed to audit clinical care standards'.¹⁰⁴¹

¹⁰³⁹ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 8, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

¹⁰⁴⁰ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 6, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

¹⁰⁴¹ Senate Community Affairs References Committee, Effectiveness of the Aged Care Quality Assessment and accreditation framework for protecting residents from abuse and poor practices, and ensuring proper

Furthermore, during its public hearings, the committee heard evidence about some aged care providers preparing for accreditation reviews.

A witness whose husband has been in a nursing home for the last four years stated:

*... when they are doing accreditation, they let them know. For two weeks they say, 'We can't do this and we can't do that, because we're preparing for accreditation.' They are like bees around a honey pot. They get good accreditation, but once that is over it is back to square one again. That is what I have a problem with.*¹⁰⁴²

In relation to the issues at the Earle Haven aged care facility in Nerang, the committee heard:

*... historically there has been an audit team coming out on a particular day or days. We have certainly seen with some aged-care providers there has been a special set of crockery and cutlery that is brought out of the cupboard for the audit days. In the case of Earle Haven, the audit crockery and cutlery was hired into the event. The culture was that it was not even worth spending enough money on that they had that there all the time.*¹⁰⁴³

Aged Care in Crisis made the following comments in its submission:

Aged care regulation was built around the accreditation system. For its first sixteen years the CEO of this system insisted that it was not a regulator but an accreditor and that accreditation and regulation were incompatible. At the same time as industry and government were boasting of our rigorous world class system its main inspector denied that it was a regulator and it did not regulate.

We compare the success of the accreditation process with the changes in staffing. At the same time as frailty increased by 53% and skilled staffing needed to care for them fell by at least 35%, the success in passing all of the 44 standards increased by 53% (from 64% to 97.8%) – near perfect scores. This would be a remarkable achievement if it was actually supported by real data but this is not the case.

*The USA collects about 175 items in an attempt to measure standards. Only 7% of their 15000 nursing homes get a perfect score and 93% fail on average about 6 to 8 of these items. Twenty percent are serious problems. In Australia, where residents get half as much care from skilled nurses and much less care overall, 98% get a perfect score and only 2% fail. The regulatory systems are different but the figures illustrate the problem. Following the 2013 re-election of a coalition government the neoliberal agenda was put back on steroids with a \$1 billion reduction in funding for regulation. This saw the number of visits by the Complaints scheme fall from 3000 a year to less than 50 and the number of accreditation visits fall by a third.*¹⁰⁴⁴

The Royal Commission was also critical of how the auditing of aged care facilities against the standards had been conducted by the ACQSC and its predecessor body. They stated that the audit reports on the service:

...do not necessarily yield information that allows a person to differentiate between barely adequate and high quality services. While auditors and assessors from the Aged Care Quality and

clinical and medical care standards are maintained and practised, Final Report, 2019, p 3, https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/AgedCareQuality/Report.

¹⁰⁴² Mrs Dell Craig, public hearing transcript, Toowoomba, 17 May 2019, p 27.

¹⁰⁴³ Aged and Disability Advocacy Australia, public hearing transcript, Benowa, 12 September 2019, p 10.

¹⁰⁴⁴ Submission 1227, attachment, p 7.

*Safety Commission may be able to differentiate between services that far exceed the standards and those that 'just fall over the line', they only report outcomes on a met or not met basis.*¹⁰⁴⁵

In regards to findings of non-compliance with the standards, the Royal Commission reported that this was 'relatively unusual':

*Since 2013, serious risk findings and sanctions have been rare, but have increased rapidly in the last two financial years. Between July 2013 and June 2017, the Australian Aged Care Quality Agency made only 41 serious risk findings and revoked the accreditation for only three providers. In contrast, there were 61 serious risk findings and 12 revocations in 2017–18 alone, the year after the Oakden scandal came to light. In 2018-19, there were nine revocations and there was a major increase in serious risk findings to 168 across the year.*¹⁰⁴⁶

11.2.4 Issues with transparency

A number of submitters to the inquiry called for increased unannounced inspections of aged care facilities by qualified officials.¹⁰⁴⁷ For example, Mr Terry Doyle submitted:

*I wish that there were more random checks on nursing homes to stop the terrible conditions some older people are living in. There should be more nurses/care givers to ensure people are not left in dirty clothes or bedding and to help those that cannot feed themselves.*¹⁰⁴⁸

In terms of encouraging choice for consumers, COTA stated:

*..the system needs to play a key role in monitoring and enforcing a culture of transparency and accountability. The dictum of consumer directed care does not lessen the responsibility of Government to provide oversight and protection to consumers. Within the context of aged care, the consumer directed approach is still new and the market is still considered 'imperfect.' The Government should play an active role as 'market steward' to ensure that people have the necessary information to be an informed, motivated and engaged consumer.*¹⁰⁴⁹

Ms Olea Kenny called for transparency on all aspects of organisations involved in aged care so that families placing their elders in care can be confident of professional standards of care. This included:

- *Information on who owns and operates these facilities*
- *Staffing levels*
- *Qualifications of staff*
- *Publication of annual financial statements (profit and loss etc)*
- *Adequate scheduled and unannounced inspections of facilities by government agencies.*¹⁰⁵⁰

¹⁰⁴⁵ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 131, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

¹⁰⁴⁶ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 62, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

¹⁰⁴⁷ Lorna Henderson, submission 2016, p 2; Dr S D'Urso, submission 310, p 2; Robert Scott, submission E114.

¹⁰⁴⁸ Submission E778.

¹⁰⁴⁹ Submission 1304, p 2.

¹⁰⁵⁰ Submission 527, p 4.

PCQ advised it supports the notion of transparency for staffing, ‘allowing prospective residents and their families to determine if a facility provides staffing levels that they believe will meet their needs and to help manage expectations’.¹⁰⁵¹

To improve transparency, members of the Upper Mt Gravatt Wishart Catholic Parish recommended:

- that all incidents/accidents or cases of negligence occurring in RACFs need to be investigated fully, documented and reported to relevant personnel including the relatives of the aged care residents
- a list of all medication, including reasons for prescribing the medication, should be available to the resident’s relative/carer¹⁰⁵²
- a registrar of staff who have been proven to be negligent within the industry be implemented to ensure that staff are not re-employed in other centres.¹⁰⁵³

The Royal Commission reported that:

*The aged care system lacks fundamental transparency. Witnesses from the Australian Department of Health told us that there is very little information available to the public about the performance of service providers. The number of complaints against them are not published. The number of assaults in their services are not published. The number of staff they employ to provide care are not published. Participation by providers in the collection of a very limited set of performance indicators only became compulsory on 1 July 2019. The Department has said that it will publish differentiated performance ratings of residential aged care providers, but there is still no clarity on what this information will look like.*¹⁰⁵⁴

In regards to the accessibility of details about providers who have not met standards, the Royal Commission stated:

*The most obvious gap in the information available to compare services is the lack of detail about their performance against the Aged Care Quality Standards. Anyone seeking details on performance against the Standards is redirected from a provider search to the ‘Compliance Information’ section of the My Aged Care website and must then search again for the service that they were interested in. If a person wants to understand more about particular issues with that service, they must then go to the Aged Care Quality and Safety Commission website and search for the audit reports on the service. This is a time-consuming and difficult process, and still does not necessarily yield information that allows a person to differentiate between barely adequate and high quality services. While auditors and assessors from the Aged Care Quality and Safety Commission may be able to differentiate between services that far exceed the standards and those that ‘just fall over the line’, they only report outcomes on a met or not met basis.*¹⁰⁵⁵

11.2.5 Issues with complaints

Some stakeholders raised the issue of the complaints process within RACFs, and suggested that residents may fear retribution if they complain.

¹⁰⁵¹ Submission 1891, p 46.

¹⁰⁵² Submission 1839, p 2.

¹⁰⁵³ Submission 1839, pp 1-2.

¹⁰⁵⁴ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 8, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

¹⁰⁵⁵ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 131, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

COTA Queensland submitted that aged care facilities may not provide adequate opportunities for residents and their families to submit complaints and feedback, and suggested that the consumer feedback process included within accreditation reviews may not be sufficient. COTA Queensland stated:

COTA Australia notes that consumers often fear retribution if they complain or advocate for their rights. Aged care residents may feel vulnerable because there is a clear power imbalance between residents and providers. In addition, COTA's research suggests that residents and their families frequently don't understand that they are able to give feedback during formal review processes.

*Adequate complaints processes, where feedback and complaints are encouraged as part of normal customer service, need to be implemented in facilities as part of a customer-service culture. The outcomes of these complaints need to be widely shared and discussed as a way of learning how to provide better quality care.*¹⁰⁵⁶

Ms Rhonda Nilsson provided a personal example based on her mother's experience in a RACF:

Residents of aged care facilities can feel intimidated by staff. There were many times that mum complained of being 'bullied' by staff and on the couple of occasions that I submitted a complaint on her behalf, this made her fearful as the particular staff member would then approach her on night shift and accuse her of making a complaint, to the point that mum asked that I not complain anymore, so the complaints process is not confidential and has repercussions on to the resident.

*Residents need an advocate, such as a regular visitor, to speak up on their behalf.*¹⁰⁵⁷

In her submission to the inquiry, Annette Davis described her interaction with the complaints process as follows:

*In October 2018 I became aware that the facility my parents were in were charging residents different Additional Fees as I had been sent another person's bill by mistake. I first raised this with the facility and no explanation was given but an offer was made to charge a reduced fee, which I accepted but it started me on an investigation as to why this was so. After finding a Federal Court Decision which was handed down on the 02/03/18 which stipulated that the manner in which the facility was charging was no longer allowed I contacted the Aged Care Commission for assistance, it is today the 01/04/19 and they still have not managed to assist me in anyway, so I can only assume that the other few hundred thousand residents in aged care are also subjected to this financial abuse although as yet they probably are not aware of it. These are not means tested fees. Additionally on the 08/10/18 a family member discovered my father in a poor state of health (I was not contacting them everyday at this stage and it is what has prompted me to speak to them everyday now). Again, I made a complaint to the ACC which has taken over 5 months to get a reasonable response from them. I believe that the poor standard that the ACC aspire to is the direct problem with aged care.*¹⁰⁵⁸

Aged Care in Crisis were critical of combining the complaints system with the regulation and accreditation systems:

The recommendation that complaints, accreditation and then later the department be amalgamated into a single regulatory authority as advised by the Productivity Commission in 2010 ignored the strong arguments previously made that accreditation and regulation were

¹⁰⁵⁶ Submission 1304, pp 17-18.

¹⁰⁵⁷ Submission 1083, p 3.

¹⁰⁵⁸ Submission E778.

*incompatible and should not be aligned. Combining three failed systems into one does not resolve any of the problems but makes it easier to control information.*¹⁰⁵⁹

The Royal Commission reported that they had:

*...heard much to show that, in practice, the complaints system is difficult to access and can be unresponsive to the concerns of complainants. Worst, we heard that people fear reprisals against those who complain by withdrawing care or otherwise mistreating the person receiving care.*¹⁰⁶⁰

11.3 An analysis of the published audit reports of Queensland aged care facilities

The committee analysed all of the audit reports of RACFs in Queensland that were published on the ACQSC website as at October 2019.¹⁰⁶¹ In all, 1,702 audit reports were reviewed, dating from 2007 onwards. The committee's analysis of these audit reports did not and could not question whether the results of each audit were an accurate representation of the standards at each RACF at the time of the inspection and audit. Instead this analysis aimed to present an overall picture on what the ACQSC (and its predecessor) has reported was the state of RACFs operating in Queensland from 2007 onwards.

11.3.1 Findings of the analysis

The analysis found the following:

- 90.2 per cent of all audit reports stated that the RACF met all standards
- there were 32 instances of the published audits reports making a 'serious risk' finding. Seventeen of these occurred in 2019, 13 were in 2018 and two were in 2017.
- 354 RACFs met all standards in all of their audits (generally conducted once every three years)
- 131 RACFs received at least one audit report where there was one or more unmet standards
- four RACFs received three audits with unmet standards
- four RACFs (3 per cent) had three audit reports with one or more unmet standards¹⁰⁶²
- nine approved providers that own multiple RACFs met all standards in all audits for each of their RACFs
- one provider, had the poorest record for approved providers who own multiple RACFs, with a quarter of all audits across their 12 facilities concluding that one or more standard were not met
- for individual RACFs, the following five facilities recorded an individual audit with the highest number of unmet standards
- for individual RACFs, six facilities recorded the highest total number of unmet standards across all of their audits from 2007 to 2019
- the following five of the former 44 standards recorded the highest number of instances of not being met across all Queensland RACFs from 2007 to 30 June 2019:

¹⁰⁵⁹ Submission 1227, attachment, p 8.

¹⁰⁶⁰ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 65, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

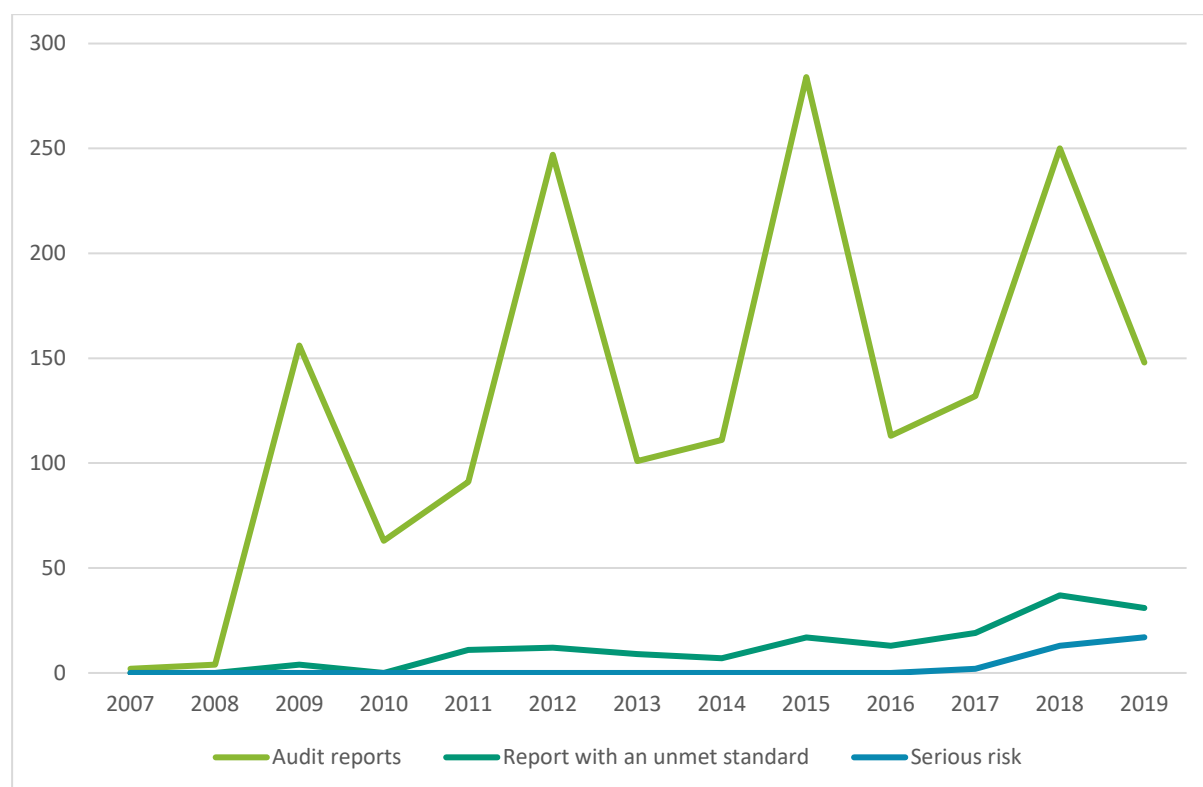
¹⁰⁶¹ Australian Government, Aged Care Quality and Safety Commission, Find a Report, <https://www.agedcarequality.gov.au/reports>.

¹⁰⁶² Note: The reports of any other RACFs that received multiple audits with unmet standards may have been removed from the Commission's website after a new approved provider took over those facilities or the RACF was closed. The Australian Department of Health has not responded to a request from the Committee for further details of these instances.

- 1.8 - Information systems
- 1.6 - Human resource management
- 2.4 - Clinical care
- 2.7 - Medication management, and
- 4.4 - Living environment
- RACFs located in South East Queensland have a higher proportion of audits with all standards being met than those located outside South East Queensland.

The chart below shows the number of published audit reports by year, along with the number of reports where there was one or more unmet standard and then the number of serious risk findings.

Figure 4: Published audit reports and their results by year (as at October 2019)



(Note the spike in the number of reports that occurred every third year – in 2009, 2012, 2015 and 2018. This illustrates the number of RACFs that starting in 2009 have generally then had only one audit report every three years.)

Source: The table is based on audit reports published by the Aged Care Quality and Safety Commission available at: <https://www.agedcarequality.gov.au/reports>.

11.4 Office of the Health Ombudsman

11.4.1 Complaints

The *Health Ombudsman Act 2013* established the Office of the Health Ombudsman (OHO) as the single point of entry for health complaints in Queensland. The OHO manages complaints about unregistered health practitioners. However, responsibility for dealing with complaints about registered health practitioners is shared with the Australian Health Practitioner Regulation Agency (AHPRA) and the National Boards.

The main objects of the *Health Ombudsman Act 2013* are:

- to protect the health and safety of the public
- to promote professional, safe and competent practice by health practitioners; and high standards of service delivery by health service organisations

- to maintain public confidence in the management of complaints and other matters relating to the provision of health services.¹⁰⁶³

Aged care services fall within the definition of a ‘health service’ under the *Health Ombudsman Act 2013* and therefore may be investigated by the Health Ombudsman.¹⁰⁶⁴

In his submission to the inquiry, the Health Ombudsman, explained:

While the OHO receives thousands of health service complaints each year (e.g. 6936 in 2017-18), complaints about aged care represent a very small proportion. Between 1 July 2014 and 18 March 2019 the OHO received only 316¹⁰⁶⁵ complaints identifying an aged care facility or organisation....

The OHO submission stated:

One reason for the low number of complaints specifically against aged care facilities received by the OHO may be that complaints are being directed in the first instance to the Commonwealth body who is the primary aged care regulator, now called the Aged Care Quality and Safety Commission (ACQSC). It is noted that the ACQSC’s primary responsibility is to assess performance against relevant standards and to manage the resolution of complaints about aged care services.¹⁰⁶⁶

11.4.2 Complaints about individual practitioners

The OHO investigates serious complaints about the conduct and performance of both registered and unregistered health practitioners. The OHO submission provided examples of practitioner issues the office has considered within an aged care context:

- *Medication management; for example, providing medication (sedation) without authority to elderly patients; or failing to follow a resident’s care plan resulting in the resident not receiving medication.*
- *Failure to adequately assess and escalate deteriorating patients; for example, delay in recognition of sepsis resulting from poor wound management or failure to recognise deterioration in a patient with significant co-morbidities.*
- *Physical assault of elderly patients; for example nurses or assistants in nursing (AINs) using excessive force against patients to obtain compliance with instructions.*
- *Other criminal conduct, such as inappropriate personal use of a patient’s credit card, theft of a patient’s property and theft of medication.¹⁰⁶⁷*

The submission noted that cases like these were isolated in nature and not indicative of any systemic trends or overall concerns.¹⁰⁶⁸ The submission further advised:

...the OHO considers that it has sufficient powers to respond to these individual cases (including the power to take immediate action to restrict practice should a practitioner pose a serious risk to persons or where it is otherwise in the public interest).

¹⁰⁶³ *Health Ombudsman Act 2013*, s 3.

¹⁰⁶⁴ *Health Ombudsman Act 2013*, s 7(2).

¹⁰⁶⁵ Unfortunately the OHO’s information system has created a challenge in being able to identify all matters specifically relating to aged care. The figure of 316 are complaints that have specifically been recorded against an aged care facility/organisation. This figure does not include where a complaint has been made against a practitioner alone (who may be working in aged care) but not against the facility.

¹⁰⁶⁶ Submission 1257, pp 1-2.

¹⁰⁶⁷ Submission 1257, p 2.

¹⁰⁶⁸ Submission 1257, p 2.

However, the OHO submission identified a regulation gap in the regulatory regime.

While the OHO can deal with serious complaints against unregistered practitioners (such as AINs or aged care workers), it does not have jurisdiction in less serious matters pertaining to unregistered practitioners. Unlike registered health practitioners, the OHO is not able to refer less serious health, conduct or performance issues pertaining to unregistered practitioners to another agency (such as AHPRA) to manage. Further, ACQSC does not have jurisdiction over individual practitioners....

....The more transient nature of the unregistered aged care workforce means that employers may not necessarily be made aware of a practitioner's prior poor conduct or unsatisfactory professional performance. Therefore, there is potentially a regulation gap regarding unregistered practitioners in relation to lower level health, conduct or performance issues that (although they do not meet the test of serious risk to others) may require some longer term management and response.¹⁰⁶⁹

11.4.3 Investigations of systemic issues

Although the Health Ombudsman is responsible for dealing with health service complaints, the office may also investigate systemic issues in the health system.¹⁰⁷⁰ The OHO submission to the inquiry explained that 'to date, the OHO's aged-care related systemic investigations (of which there have been two) have related to specific individual facilities and not to the system more broadly'.¹⁰⁷¹

The submission also provided examples of individual facility based systemic issues raised with the OHO including:

- *Deficiencies in compliance with medication policies and procedures; for example having an unregistered and unqualified person administering medication.*
- *Failure to appropriately manage the risk of falls, including assessment of the physical environment and adequate supervision of patients.*
- *Inadequate assessment of acutely unwell patients who have dementia or other cognitive impairments resulting in ineffective or inappropriate treatment.*
- *Failure to ensure the completion of thorough and appropriate initial health assessments and post incident assessments (e.g. following falls).¹⁰⁷²*

The OHO will 'typically refer complaints about facilities that are suggestive of systemic issues to the ACQSC. From 1 July 2014 to 18 March 2019, the OHO has consulted on and referred 55 complaints to this agency'.¹⁰⁷³

11.5 Investigation by the Coroner

The death of an aged care resident will be reportable to the coroner only if it is a 'reportable death' under the *Coroners Act 2003*. This means the circumstances of the death must meet one or more of the following specific criteria:

- *the person's identity is not known*
- *the death is violent or unnatural or occurred in suspicious circumstances*
- *the death is health care related*

¹⁰⁶⁹ Submission 1257, p 3.

¹⁰⁷⁰ *Health Ombudsman Act 2013*, s 11.

¹⁰⁷¹ Submission 1257, p 3.

¹⁰⁷² Submission 1257, p 3.

¹⁰⁷³ Submission 1257, p 3.

- *the probable cause of death is not known and a cause of death certificate cannot be issued*
- *the death occurred “in care”*
- *the death occurred in custody or in the course of a police operation.*¹⁰⁷⁴

The Queensland courts’ website advises:

In practice, deaths of aged care residents are most commonly reported because they died:

- *from an “unnatural” cause, for example, traumatic injury (often sustained in a mechanical fall), airway obstruction by food bolus, suicide or the death occurred in suspicious circumstances;*
- *as the unexpected result of a health care investigation or failure to provide health care, for example inadequate swallow/aspiration risk management or chronic wound/pressure area management, medication error or delayed medical treatment; or*
- *from an unknown cause.*¹⁰⁷⁵

In her submission to the inquiry the Public Advocate, Mary Burgess made the following comments in relation to the role of the Coroner:

*The final potential oversight mechanism available for the protection of consumers of aged care services, is the investigation of aged care deaths by the Coroner when the death may be related to the quality of care provided at a residential aged care facility.*¹⁰⁷⁶

However, her submission outlined the limitations of the Coroner’s role in aged care deaths:

*Currently there is no system or framework in Australia for reviewing deaths in residential aged care facilities unless a number of circumstances ... make the death reportable to the Coroner.*¹⁰⁷⁷

She recommended the state government:

*... consider including deaths in residential aged care facilities across the State as reportable deaths in the Coroners Act 2003, similar to the reportable deaths of people with disability living in care and receiving certain classes of support under the National Disability Insurance Scheme (NDIS).*¹⁰⁷⁸

Committee comment

The audit process for residential aged care facilities needs to be improved. The criteria covered by audits should be expanded to cover more aspects of facilities’ operations that have a direct bearing on the quality of care provided to residents.

For accreditation reports the current system of pass/fail for compliance with standards provides little information and should be replaced with a graded system of results to more accurately reflect the audit findings. The accreditation system should also be separated from the regulatory system. This has been recommended by previous reviews.

The practice of providing prior notice to providers of compliance audits of facilities should cease. As part of the audit process, the findings should be shared with residents and their representatives for

¹⁰⁷⁴ Coroners Act 2003, s 8(3).

¹⁰⁷⁵ Department of Justice and Attorney-General, Information sheet, Deaths of aged care residents, https://www.courts.qld.gov.au/__data/assets/pdf_file/0010/630676/m-ccq-deaths-of-aged-care-residents.pdf.

¹⁰⁷⁶ Submission 1208, pp 9, 10.

¹⁰⁷⁷ Submission 1208, pp 9, 10.

¹⁰⁷⁸ Submission 1208, pp 9, 10.

comment before finalising the audits. This would help to check whether the findings are accurate. As part of the audit process, residents and their representatives should be notified by the Aged Care Quality and Safety Commission and provided with information about how to contribute to the audit process.

The publication of audit reports is an important mechanism for ensuring transparency. The Aged Care Quality and Safety Commission should publish with those accreditation reports a statement to explain which reports have not been published and the reasons for non-publication. Further, it should explain its practices in relation to the publication of reports for accreditations of facilities conducted while the facilities were owned by different provider entities. Better public reporting and increased transparency would assist persons to make informed decisions about their choice of residential aged care facilities.

The complaints system for aged care should be made more accessible and responsive. The complaints system should also provide a mechanism to encourage medical practitioners and allied health professionals to report problems they observe, on a confidential basis if necessary, to the Aged Care Quality and Safety Commission.

To further improve transparency in relation to staffing at residential aged care facilities, the providers should disclose to residents, prospective residents and their representatives the qualifications, training and experience of their staff.

The Health Ombudsman identified gaps in the coverage of complaints and other issues related to aged care in Queensland. The committee agrees with the Health Ombudsman, and recommends that the Queensland Government consider legislating to provide the Health Ombudsman with the power to refer less serious health, conduct or performance issues pertaining to unregistered practitioners to another agency such as Australian Health Practitioner Regulation Agency.

At the core of many issues identified by stakeholders with the standard of aged care is the lack of adequate staffing. The committee believes the Australian Government should set minimum staff to patient ratios for residential aged care facilities.

Recommendation 28 Expanded criteria for audits of residential aged care facilities

The committee recommends that the Australian Government require that the criteria covered by audits of residential aged care facilities be expanded to cover internal processes, resident safety, capacity to meet residents' needs and the standard of accommodation.

Recommendation 29 Graded scale for compliance with aged care standards

The committee recommends that the Australian Government require that the current system of pass/fail for compliance with standards be replaced with a graded system.

Recommendation 30 Separation of accreditation and compliance systems

The committee recommends that the Australian Government require that the accreditation system is separated from the regulatory system.

Recommendation 31 No prior notice of audits of facilities

The committee recommends that the Australian Government cease the practice of providing prior notice to providers of compliance audits of residential aged care facilities.

Recommendation 32 Ground truthing of audit findings by residents

The committee recommends that the Australian Government require that, as part of the audit process, residents and their representatives are provided with the opportunity to contribute to the audit process and audit findings are shared with residents and their representatives for comment before finalising the audits.

Recommendation 33 Publication of compliance monitoring reports

The committee recommends that the Australian Government require the Aged Care Quality and Safety Commission to publish all compliance monitoring update reports.

Recommendation 34 Publication of accreditation reports after a change of provider

The committee recommends that the Australian Government require the Aged Care Quality and Safety Commission to explain the commission's practices in relation to the removal from publication of accreditation reports of facilities after any change of approved provider occurs.

Recommendation 35 More accessible complaints system

The committee recommends that the Australian Government require that the Aged Care Quality and Safety Commission's complaints system for aged care be made more accessible and responsive to complaints.

Recommendation 36 Process for medical practitioners to report problems

The committee recommends that the Australian Government require that the Aged Care Quality and Safety Commission's complaints system promote mechanisms to encourage medical practitioners and allied health professionals to report problems they observe with the potential to compromise the safety and welfare of residents and other clients, on a confidential basis if necessary.

Recommendation 37 Disclosure of staff qualifications and experience

The committee recommends that the Australian Government require that providers of residential aged care services disclose to residents, prospective residents and their representatives the qualifications, training and experience of their staff at the facility.

12 Aged Care Workforce

Aged care is a growth industry. The Productivity Commission predicts that 3.5 million Australians will be accessing aged care services every year by 2050. With such rapid growth expected to occur in the sector, ensuring that older Australians receive quality, compassionate and respectful care requires the aged care industry to adopt modern practices to recruit a workforce with the right attitude and skills.¹⁰⁷⁹

The National Aged Care Workforce Census and Survey is conducted approximately every four years. The 2016 census reported the number of paid workers in the aged care industry was around 366,000, with an additional 68,000 volunteers. When the census was conducted in 2012, the number of paid workers was 240,000.¹⁰⁸⁰

Appropriate planning for a well-supported and qualified aged care workforce is particularly important given projections about the need for expansion of the aged care workforce as the population ages. Some estimates suggest that, by 2050, the number of employees engaged in the provision of aged care will account for 4.9% of all employees in Australia.¹⁰⁸¹

An independent Aged Care Workforce Strategy Taskforce was tasked with developing a strategy for growing and sustaining that workforce that provides aged care services and support for older people, to meet their care needs in a variety of settings across Australia. The work of the Taskforce was supported by a \$1.92 million Australian Government funding commitment.

The Taskforce spent eight months gathering evidence which included a national community and sector engagement approach, across Australia. The general public, the workforce and aged care sector subject matter experts were invited to have their say in the future of Australia's aged care workforce.¹⁰⁸²

On 29 June 2018, the Aged Care Workforce Strategy Taskforce delivered *A Matter of Care – Australia's Aged Care Workforce Strategy*, to the Minister for Senior Australians and Aged Care. The strategy is industry focused and identifies 14 different strategic actions to help the aged care industry to address the current and future workforce challenges, including attracting, training and retaining skilled staff to work in aged care services. The 14 strategic actions are:

1. Creation of a social change campaign to reframe caring and promote the workforce.
2. Voluntary industry code of practice
3. Reframing the qualification and skills framework – addressing current and future competencies and skills requirements
4. Defining new career pathways including accreditation
5. Developing cultures of feedback and continuous improvement

¹⁰⁷⁹ Australian Government, Productivity Commission, *Caring for Older Australians: Productivity Commission Inquiry Report No. 53*, 28 June 2011, <https://www.pc.gov.au/inquiries/completed/aged-care/report/aged-care-overview-booklet.pdf>.

¹⁰⁸⁰ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 26, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

¹⁰⁸¹ Australian Government, Australian Law Reform Commission, *Elder Abuse – A National Legal Response: ALRC Report 131*, <https://www.alrc.gov.au/publications/aged-care-workforce>.

¹⁰⁸² Australian Government, Department of Health, *Australia's Aged Care Workforce Strategy, At a Glance – the fourteen Strategic Actions*, https://www.health.gov.au/sites/default/files/a-matter-of-care-australia-s-aged-care-workforce-strategy-at-a-glance-the-14-strategic-actions-of-australia-s-aged-care-workforce-strategy_0.pdf.

6. Establishing a new standard approach to workforce planning and skills mix modelling
7. Implementing new attraction and retention strategies for the workforce
8. Developing a revised workforce relations framework to better reflect the changing nature of work
9. Strengthening the interface between aged care and primary/acute care
10. Improved training and recruitment practices for the Australian Government aged care workforce
11. Establishing a remote accord to develop pathways for change involving all levels of government, industry and the community
12. Establishing an Aged Care Centre for Growth and Translational Research
13. Current and future funding considerations, including staff remuneration
14. Transitioning the existing workforce to new standards.¹⁰⁸³

Stakeholders expressed support for the implementation of the strategy.¹⁰⁸⁴ ADA Australia advised it encourages the Queensland Government to support the Strategy by investing in Department of Employment, Small Business and Training initiatives that align the key strategic actions outlined in the Strategy.¹⁰⁸⁵ LASA also advised that it 'supports the investment in a skilled workforce in line with recommendations from the *Aged Care Workforce Taskforce Strategy Report (Aged Care Workforce), A Matter of Care*'.¹⁰⁸⁶ Anglicare SQ also called for commitment to public investment to implement the Aged Care Workforce Strategy Taskforce Report, 'to create an aged care workforce that is properly paid, valued and specialised with clear career pathways'.¹⁰⁸⁷

The Aged Services Industry Reference Committee (IRC) has since been established to respond to relevant recommendations in the Aged Care Workforce Strategy and to ensure that the national education and training system is able to deliver an agile workforce that can provide safe and quality care to older Australians in a variety of settings. This includes addressing the current and future competencies and skill requirements for new workers entering the sector and existing staff needing to upskill in both the vocational education and training (VET) and higher education sectors.¹⁰⁸⁸

The Aged Services IRC is responsible for:

- reforming national training package qualifications and skill sets needed by the aged services industry
- examining new approaches to career structuring and progression in the sector, and the education pathways needed to support these
- scoping opportunities for collaboration across VET, higher education and a range of industry sectors to tackle the challenges of an ageing society

¹⁰⁸³ Australian Government, Department of Health, *A Matter of Care: Australia's Aged Care Workforce Strategy - At a Glance – the fourteen Strategic Actions*, https://www.health.gov.au/sites/default/files/a-matter-of-care-australia-s-aged-care-workforce-strategy-at-a-glance-the-14-strategic-actions-of-australia-s-aged-care-workforce-strategy_0.pdf.

¹⁰⁸⁴ Submission 1309, p 6.

¹⁰⁸⁵ Submission 1243, p 9.

¹⁰⁸⁶ Submission 1283, p 3.

¹⁰⁸⁷ Submission 1229, p 6.

¹⁰⁸⁸ Australian Industry and Skills Committee, Aged Services Industry Reference Committee, <https://www.aisc.net.au/irc/aged-care-industry-reference-committee>.

- working with other IRCs which have an interest in qualifications relevant to the aged services sector to ensure industry needs are considered and met.¹⁰⁸⁹

12.1 Workforce composition

The 2016 aged care workforce census noted that the residential aged care workforce in Australia was ageing and was, on average, older than the Australian workforce as a whole.¹⁰⁹⁰ It is interesting to note that the average age of the residential care workforce decreased from 48 to 46 between 2012 and 2016. In contrast, the average age of the workforce in home support and home care increased from 50 in 2012 to 52 in 2016.¹⁰⁹¹

Overseas born workers continue to make up a very significant proportion of the aged care workforce. In 2016, the proportion in residential care was highest with 32 per cent of workers born overseas, while in home support and home care the proportion was 23 per cent. This compares with 35 per cent in residential care and 28 per cent in home support and home care in 2012.¹⁰⁹²

Although aged care remains a female dominated industry, the proportion of males in the workforce is continuing to grow, albeit slowly and from a small base. In residential care, 13 per cent of workers were male (compared with 11 per cent in 2012). In the home support and home care sectors, men represented 11 per cent of all workers (10 per cent in 2012).¹⁰⁹³

12.2 Workforce training

Workforce training and education is a shared responsibility between government and industry.¹⁰⁹⁴ As mentioned earlier, aged care providers have obligations under the Aged Care Act to ensure that there are adequate numbers of appropriately skilled staff to meet consumers' individual care needs.¹⁰⁹⁵

Deloitte reported that there is increasing demand for a more highly skilled aged care workforce as older Australians enter residential care at later stages and with more complex medical conditions and comorbidity, stating:

This is already apparent in parts of the workforce, with 62% of residential facilities reporting a skills shortage of registered nurses. Our consultations with providers of residential aged care

¹⁰⁸⁹ Australian Industry and Skills Committee, Aged Services Industry Reference Committee, <https://www.aisc.net.au/irc/aged-care-industry-reference-committee>.

¹⁰⁹⁰ Australian Government, Department of Health, *The Aged Care Workforce*, 2016, March 2017, p 12, https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/03_2017/nacwcs_final_report_290317.pdf.

¹⁰⁹¹ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 27, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

¹⁰⁹² Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 27, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

¹⁰⁹³ Aged Care Financing Authority, *Seventh report on the Funding and Financing of the Aged Care Industry 2019*, p 27, <https://www.health.gov.au/resources/publications/2018-19-report-on-the-operation-of-the-aged-care-act-1997>.

¹⁰⁹⁴ National Institute of Labour Studies, *2016 National aged care workforce census and survey – the aged care workforce*, 2017, pp 158-9, <https://www.gen-agedcaredata.gov.au/Resources/Reports-and-publications/2017/March/The-aged-care-workforce,-2016>.

¹⁰⁹⁵ Australian Government, Department of Health, Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia's Aged Care Workforce Strategy*, 2019, p 9, <https://www.health.gov.au/sites/default/files/a-matter-of-care-australia-s-aged-care-workforce-strategy.pdf>.

*services indicated that admitting residents with higher care needs on average means that providers need to upskill their workforce.*¹⁰⁹⁶

12.2.1 Australian Government funded training and support programs

Since 2002, successive governments have funded various types of workforce programs.

The Aged Care Workforce Fund was introduced in 2011 with the aim of improving quality of aged care by providing a flexible pool of funds for initiatives that improve the skills of the aged care workforce. The fund provided access to education, training and other form of supports (for example, nursing scholarships and financial support for aged care providers to provide training places), and targeted training and development for priority groups, including for Aboriginal and Torres Strait Islander peoples.¹⁰⁹⁷

In 2015, the Federal Government announced that the Aged Care Workforce Fund would be combined with health workforce funding into a single Health Workforce Program.¹⁰⁹⁸

In May 2019, the Aged Care Workforce Industry Council was set up to lead the implementation of the Aged Care Workforce Strategy, including working with industry to respond to the actions contained in the strategy.¹⁰⁹⁹

An Aged Services IRC has also been established to respond to relevant recommendations in the Aged Care Workforce Strategy and to ensure that the national education and training system is able to deliver an agile workforce that can provide safe and quality care to older Australians in a variety of settings. This includes addressing the current and future competencies and skill requirements for new workers entering the sector and existing staff needing to upskill in both the vocational education and training (VET) and higher education sectors.

The Royal Commission noted:

*In the 2017–18 Budget, the Government announced funding of \$1.9 million over two years to support the Aged Care Workforce Taskforce to develop an Aged Care Workforce Strategy. \$33 million over three years was allocated for the Boosting the Local Care Workforce Program. The new program aims to develop the capacity of disability and aged care service providers to operate effectively and expand their business offerings and workforces.*¹¹⁰⁰

12.2.1.1 Indigenous employment programs

All existing Indigenous aged care workforce-specific programs continued during 2018–19. These programs are outlined in the table below.

¹⁰⁹⁶ Deloitte Access Economics, *Australia's Aged Care Sector: Economic contribution and future directions*, Aged Care Guild, June 2016, p 32, <https://www2.deloitte.com/au/en/pages/economics/articles/australias-aged-care-sector-economic-contribution.html>.

¹⁰⁹⁷ Royal Commission into Aged Care Quality and Safety, *Navigating the maze: An overview of the Australia's current aged care system*, Background paper 1, p 27, <https://agedcare.royalcommission.gov.au/publications/Documents/background-paper-1.pdf>.

¹⁰⁹⁸ Australian Government, Department of Health, *Future of Australia's Aged Care Sector Workforce*, pp 21-22.

¹⁰⁹⁹ Australian Government, Department of Health, Aged Care Workforce Industry Council, <https://www.health.gov.au/contacts/aged-care-workforce-industry-council>.

¹¹⁰⁰ Royal Commission into Aged Care Quality and Safety, *Navigating the maze: An overview of the Australia's current aged care system*, Background paper 1, p 27, <https://agedcare.royalcommission.gov.au/publications/Documents/background-paper-1.pdf>.

Table 17: Indigenous employment programs and funding, 2018–19

Title	Description	Funding \$M
Indigenous Employment Initiatives (IEI)	Provides aged care jobs across Australia to more than 750 Aboriginal and Torres Strait Islander people in Indigenous-specific aged care services in rural and remote locations.	20.7
The Rural and Remote Training Program (RRTP), and the Northern Territory Training Program (NTP)	These programs provide culturally appropriate, targeted and accredited aged care training to Aboriginal and Torres Strait Islander aged care workers in rural and remote locations in WA, SA, NT and Qld.	6.1
Indigenous Remote Service Delivery Traineeships (IRSDT)	Aims to build business and management capacity of Indigenous aged care and primary health care services in remote areas. Approximately 295 trainees have received qualifications since the inception of the program.	4.3
Aged Care Education and Training Incentive (ACETI)	Provides direct benefits to aged care workers who undertake further studies to enhance their career as a personal care worker, an enrolled nurse or a registered nurse. (ACETI ceased for new students after 31 March 2016).	3.0

Source: Australian Government, Department of Health, 2018–19 Report on the Operation of the Aged Care Act 1997, p 75.

12.2.1.2 *Dementia and Aged Care Services Fund*

The DACS Fund provided funding for the Dementia Training Program, which provided more than 26,000 occasions of targeted dementia training for staff in residential and in-home care as well as acute and primary care health sectors in 2018–19.¹¹⁰¹

12.3 Workforce pay and conditions

In 2011, the Australian Productivity Commission proposed that scheduled care prices take into account the need to pay fair and competitive remuneration and provide satisfying working conditions. The Australian Productivity Commission also supported the development of more attractive career paths, opportunities for professional development, improved managerial expertise and a review of registered training organisations to ensure the quality of delivery of accredited courses.¹¹⁰²

A study undertaken by Curtin University revealed that around 90 per cent of aged care employees are female, and the average age of the workforce is considerably older than the overall Australian workforce. In the residential care sector around 70 per cent of workers are classified as personal care assistants and over 70 per cent of employees are on permanent part-time contracts. The hourly rates of pay for care assistants are among the lowest across all occupational groups.¹¹⁰³

¹¹⁰¹ Australian Government, Department of Health, 2018–19 Report on the Operation of the Aged Care Act 1997, p 76, https://www.gen-agedcaredata.gov.au/www_ahwgen/media/ROACA/2017%E2%80%9318-Report-on-the-Operation-of-the-Aged-Care-Act%E2%80%931997.pdf.

¹¹⁰² Productivity Commission, Caring for Older Australians, Report No 53, 2011, Vol 2, pp 354–357, <https://www.pc.gov.au/inquiries/completed/aged-care/report>.

¹¹⁰³ Bankwest Curtin Economics Centre, Developing Sustainable Pathways for Aged Care Workers: A WA Case Study, BCEC Research Report No. 13/18, April 2018, p 6, <https://bcec.edu.au/assets/BCEC-Report-Developing-sustainable-career-pathways-for-aged-care-workers.pdf>.

To stay in the sector the most important factors were seen as pay, job security, guaranteed hours and opportunities for promotion. The most important factors that encouraged exit were issues around workload, staffing and team work, followed by the prospect of getting a better paid job elsewhere.¹¹⁰⁴

12.4 Workforce issues and challenges

The Aged Care Workforce Strategy, *A Matter of Care*, lists the following as considerable challenges within the aged care industry:

- High employee turnover, including significant movement between organisations
- Poor employee engagement and enablement
- Difficulty in attracting talent
- Ineffective and inefficient design of work organisation and jobs
- Undervalued jobs with poor market positioning
- Suboptimal workforce planning
- Casualisation of the workforce, particularly in home-based care
- Leadership effectiveness gaps
- Key capability gaps and skills and competencies misalignment
- Career progression bottlenecks
- Ineffective recruitment, induction and on-boarding processes.¹¹⁰⁵

The report further notes that these challenges are amplified outside major cities and metropolitan areas, particularly in remote and very remote settings.¹¹⁰⁶

Staffing of the aged care sector was a main consideration of the Royal Commission. It noted evidence had been provided which raised concerns with identifying, recruiting, training and retaining suitable skilled staff.¹¹⁰⁷

The Royal Commission noted the issue of staffing is ‘one of the main and ongoing challenges for providers in regional and remote locations’¹¹⁰⁸ and reported:

Witnesses described cultural and geographical barriers to providing a quality aged care workforce, including limited access to training providers in remote locations, limited career

¹¹⁰⁴ Bankwest Curtin Economics Centre, Developing Sustainable Pathways for Aged Care Workers: A WA Case Study, BCEC Research Report No. 13/18, April 2018, p 6, <https://bcec.edu.au/assets/BCEC-Report-Developing-sustainable-career-pathways-for-aged-care-workers.pdf>.

¹¹⁰⁵ Australian Government, Department of Health, Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia’s Aged Care Workforce Strategy*, 2019, p 5.

¹¹⁰⁶ Australian Government, Department of Health, Aged Care Workforce Strategy Taskforce, *A Matter of Care – Australia’s Aged Care Workforce Strategy*, 2019, p 5.

¹¹⁰⁷ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 186, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

¹¹⁰⁸ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 186, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

*progression opportunities, restrictions on flexible staffing between residential and home care services, and negative perceptions of the aged care sector.*¹¹⁰⁹

Stakeholders to the inquiry also raised a number of issues in relation to the training received by the aged care workforce both prior to entering and while working in the sector, the difficulties in attracting and retaining staff, the pay and conditions of the aged care workforce and the impact of an ageing workforce.

12.4.1 Training

A number of stakeholders called for the quality of the training for people entering the aged care workforce to be improved, such as through the integration of work experience, training in the needs of elderly patients, and the need to provide ongoing training.

12.4.1.1 The quality of the training

SVHA raised as an issue the distribution and lack of a specialised and skilled aged care workforce, submitting:

*A key challenge in Queensland's aged care system is the uneven distribution of specialised, well-trained and job-ready professionals who are experienced in geriatric care, ranging from healthcare workers to personal care/community care workers. It is critical that residents have access to the necessary skillset in the workforce, particularly for those clients who may be experiencing disorders such as dementia and/or requiring palliative care when they need it.*¹¹¹⁰

Particular issues were raised with the training provided to PCWs. For example, the QLS made the following comment:

*... this position requires little if any formal qualifications, however, it would be preferable for the position to be filled by a person holding a minimum of a Certificate III in aged care, which includes a mandatory practical placement component. Often there is no formal education or cultural awareness qualification required, and alternative courses may be only comprised of online modules without any pre-requisite personal interaction. The award for a PCW fulltime worker level 1 is \$20.12/hr, and increases to level 7 at \$24.44/hr.*¹¹¹¹

Reverend Stefan Slucki referred to the short duration of some training programs, suggesting that these courses do not provide adequate and appropriate training, particularly for overseas-born workers. He submitted 'this is woefully inadequate especially to prepare them for dealing with dementia-affected residents'.¹¹¹²

Ms Lorna Henderson commented that training was variable, stating 'Since private companies have been offering school like or online training the training standard has dropped'.¹¹¹³

PCQ submitted that whilst there has been an influx of professional caregivers in to the market due to an increasing number of places available for people to complete a Certificate III in Individual and Personal Support, the quality of staff is an ongoing issue, stating:

¹¹⁰⁹ Royal Commission into Aged Care Quality and Safety, Interim Report: Neglect, Volume 1, p 186, <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>.

¹¹¹⁰ Submission 1280, p 11.

¹¹¹¹ Submission 1201, p 3.

¹¹¹² Submission 1680, p 3.

¹¹¹³ Submission 2016, p 1.

*Newly qualified care staff require significant mentorship and support for their first 12 months. This is placing increasing burden on aged care organisations, and particularly experienced aged care staff within those organisations.*¹¹¹⁴

Churches of Christ recommended that registered training organisations who train most aged care staff, will need to continue to engage closely with the sector to ensure their graduates are ‘fit for purpose’ when they complete their certificate level training.¹¹¹⁵

A number of stakeholders called for work experience to be included in the training of aged care workers. For example, CentaCareCQ submitted:

*While training has improved in recent years, there are still instances of people coming into roles with appropriate qualifications but unable to perform the work because of the lack of experience built into the training packages. As people are living longer and home care packages are increasing in complexity, the need for workers to be exposed to high needs and complex client work prior to being rostered to provide supports will become greater.*¹¹¹⁶

To address this, CentaCare CQ called for:

- more experiential learning e.g. increase traineeships rather than certificates, to provide on the job training while becoming qualified, and
- internships or placements in high needs facilities for currently skilled workers in the home care workforce, to ensure readiness to work with higher needs clients in home care.¹¹¹⁷

SVHA submitted that staff need to be “job-ready” upon graduation, stating:

...there is an opportunity to evolve the current vocational education and health professional pathways so that individuals can obtain valuable work experience and exposure to this sector early and more frequently throughout their training, including when GPs complete specialist training.

This may help improve number of health professionals and community care workers considering a career in aged care as well with the supply and retention of a skilled, job-ready, and committed workforce.

*One idea to improve the job readiness of aged care staff includes evolving current medical, health and community care training frameworks so that students have earlier placements and additional modules in aged care services in their course.*¹¹¹⁸

Ms Joanne O’Shanesy called for apprenticeships for aged and disability direct care staff and scholarships for allied health professionals.¹¹¹⁹

Brisbane South PHN stated that aged care needs to be established as a specialist nursing area, and could be advanced through an aged care nursing graduate program.¹¹²⁰

12.4.1.2 Lack of training in the specifics of aged care

Another significant issue raised by stakeholders in relation to workforce training was the lack of focus on the particular needs of elderly people, particularly in relation to dementia and palliative care.

¹¹¹⁴ Submission 1891, p 48.

¹¹¹⁵ Submission 1281, p 6.

¹¹¹⁶ Submission 1297, p 6.

¹¹¹⁷ Submission 1297, p 6.

¹¹¹⁸ Submission 1280, p 15.

¹¹¹⁹ Submission 1791, p 3.

¹¹²⁰ Submission 1212, p 4.

LASA advised the committee in its submission:

*The aged care workforce includes a mix of skills and skill levels such as personal care workers, enrolled nurses, registered nurses, nurse practitioners, allied health professionals, and support staff. Thus there are varying levels of training depending on the role the staff member is undertaking. However, concern exists that education for entry into the nursing profession does not include a sufficient component about health care in ageing. Vocational training for Personal care workers has been found to vary in quality and to lack some necessary content. However, a number of steps have been undertaken to review and improve workforce training and workforce supply issues in aged care.*¹¹²¹

CentaCareCQ called for an increase in training content on the processes/ continuum of ageing, so that workers have a greater understanding of the changes that will happen for their clients¹¹²²

Woombye Care similarly called for the education that is provided to the aged care sector to be improved, and also suggested that funded education opportunities be offered to qualified professionals to increase their knowledge to benefit the aged care sector and develop better education in nursing studies around aged care and dementia.¹¹²³

Upper Mt Gravatt Wishart Catholic Parish also submitted that staff be required to be trained adequately to meet the needs of those in aged care, stating:

*Staff need adequate training to be able to deal with situations that may arise. It is important that they understand the medical, physical and cultural needs of the residents...It is important that staff know how to communicate effectively with those residents who are hearing impaired (need to face the person; use strong voice) or due to language barrier have difficulty in being able to communicate their feelings or needs.*¹¹²⁴

Ms Michelle Cross provided a personal example when calling for extensive training for staff to enable them to provide the care for each individuals needs:

*My Mum has macular and semantic dementia. On entering aged care staff seemed oblivious/ignorant to Mum's personal need - her lack of eyesight nor her declining cognitive ability never seemed to be considered hence situations arose that should never have i.e. Mum trying to toilet herself, these episodes are absolutely degrading for our Mum.*¹¹²⁵

AASW Qld Branch submitted that due to medical advancements and complexity of psychosocial care needs:

*many people in residential aged care require specialist assistance. For example, there is an increasing need for expertise and skills in tracheostomies, ventilator dependence, and behaviour management. There are very limited facilities that have the trained staff required to care for these cohorts.*¹¹²⁶

Woombye Care submitted that the aged care industry needs very skilled professionals due to a lack of direct support from medical professionals, and raised concerns about the current training, submitting:

...there is minimal proper education given in TAFE and university degrees specifically about ageing and more specifically about dementia. Regardless of whether people work in the Aged

¹¹²¹ Submission 1283, p 3.

¹¹²² Submission 1297, p 6.

¹¹²³ Submission 1254, p 3.

¹¹²⁴ Submission 1839, p 1.

¹¹²⁵ Submission E226.

¹¹²⁶ Submission 1288, p 16.

*Care sector, they will likely look after an elderly person in their career and need to have a better understanding of the ageing process and dementia.*¹¹²⁷

A number of stakeholders expressed the view that training in mental health and dementia needs to be included in the training of aged care sector workers, but is currently lacking in the existing training options.

ADA Australia submitted that residential care staff are often not skilled in understanding and responding to resident's mental illness/cognitive decline, and are often too busy to have meaningful engagement with residents, resulting in mental illness going unrecognised. They submitted that 'Staff training on understanding, engaging supporting people living with mental illness/decline is essential'.¹¹²⁸

AASW Qld Branch similarly submitted:

*...not all aged care providers have the skills or knowledge to understand mental illness and adopt strategies to provide appropriate support. Care workers can also struggle to communicate effectively with these clients. Staff in community and residential aged care need to be able to access training and support for working with people with significant mental health issues that impact on their daily living and the care they are receiving.*¹¹²⁹

SVHA stated that with challenging complex behaviours, there will be a need to strengthen the skills, training and experience of the aged care workforce, so they are able to deliver the appropriate care to elderly residents.¹¹³⁰

Dementia Australia submitted that the key enabler to a successful aged care system is its workforce, yet the general capacity of the workforce to meet the needs of people with dementia is hampered by a lack of consistent education and training. Dementia Australia submitted:

Personal care attendants (PCAs) and community care workers make up the majority of the aged care workforce (according to Department of Health statistics, PCAs make up 70 percent in residential care while community care workers accounts for 84 percent of community care workers, respectively) and the majority of these workers hold a Certificate III in Aged Care (individualised support). However, because of the way the current qualifications are structured, dementia-specific education is at best offered as an elective and there is no mandatory component within their training.

*Given the rapidly increasing prevalence of dementia, embedding dementia specific education into training should be made mandatory requirement. Understanding the symptomology and challenges people with dementia face, in addition to the appropriate care that is needed to support someone living with dementia are necessary skills, without which, we cannot expect health and care professionals to deliver the standard of care that people with dementia need and deserve.*¹¹³¹

National Seniors Australia stated that direct care staff need to have, at the very least, a basic understanding of how to interact with and treat people who have dementia, and advocated for all direct care staff to have basic dementia training. They submitted:

¹¹²⁷ Submission 1254, p 2.

¹¹²⁸ Submission 1243, p 7.

¹¹²⁹ Submission 1288, p 7.

¹¹³⁰ Submission 1280, p 11.

¹¹³¹ Submission 1621, pp 7-8.

*It essential that people caring for residents who suffer from dementia understand the behaviour associated with this condition and receive training that is appropriate and adequate to prepare them to work in such environments.*¹¹³²

HammondCare observed that inadequate and poor-quality training, particularly in dementia care, has been a recurring theme in the Royal Commission. HammondCare submitted there is a:

*need for better alignment of funded programs to support the development of the aged care workforce. The Queensland and Federal Government must maintain budgeted funding in the forward estimates for targeted aged care and dementia education initiatives.*¹¹³³

PCQ also raised the issue of a lack of knowledge of palliative care among residential aged care staff, submitting:

*Personal Care Assistant knowledge found to be no different to ancillary staff i.e. laundry, food services, and maintenance staff (Ford & McInerney, 2011). This is particularly alarming when most of the care providers in the residential care sector are Personal Care Assistants. Further work on translating evidence on end-of-life care into practice in the residential aged care sector is required.*¹¹³⁴

The AASW Qld Branch indicated there is a growing need for staff education and skills to appropriately manage people's psychosocial care in the context of palliative and end-of-life care, but acknowledged that capacity to provide this care and these skills are impacted by the current aged care funding model, which only provides funding for palliative care in the final week or days of a person's life.¹¹³⁵

SVHA stated that 'universities and vocational education institutions must graduate students with knowledge and skills that meet the future skill requirements of the aged care sector. This should include incorporating new modules of learning with an emphasis on dementia and palliative care'.¹¹³⁶

12.4.1.3 Lack of ongoing training for aged care workers

A number of stakeholders commented on the lack of ongoing training for aged care workers, and particularly noted that training is expected to be done in the worker's own time.

PCQ advised the committee:

Other than initial training for professional caregivers, PCQ is not aware of any ongoing, standardised education or training beyond the mandatory annual health and safety training. Registered and enrolled nurses in aged care are subject to the Australian Health Professional Registration Authority (AHPRA) rules regarding continuing professional education (a minimum of 20 hours per year).

*PCQ's members report that education and training opportunities depend on the individual facility manager or organisational education policy. Staff are generally expected to attend education in their own time (unpaid). PCQ would like to see mandatory training and education introduced for palliative care and dementia care for all staff working in residential aged care (clinical and ancillary).*¹¹³⁷

Queensland PHNs commented that aged care staff face a range of barriers to accessing training and the level of training undertaken by the majority of staff doesn't support the early identification of a deteriorating resident until they are acutely unwell. Queensland PHNs called for staffing numbers to

¹¹³² Submission 1309, p 5.

¹¹³³ Submission 1261, p 6.

¹¹³⁴ Submission 1891, p 39.

¹¹³⁵ Submission 1288, pp 16-17.

¹¹³⁶ Submission 1280, p 14.

¹¹³⁷ Submission 1891, p 49.

be sufficient to allow the release of staff to attend professional development opportunities without impacting on the care provided to residents. Qld PHNs also called for non-compliance training to be seen as necessary for quality care provision as it is in the health sector.¹¹³⁸

HammondCare submitted that in order to provide meaningful career progression to people working in aged care, it is necessary to provide opportunities for employees of all levels and qualifications to specialise their skills. HammondCare suggested:

*Not everyone can progress their career in a conventional sense, through promotion, but all care staff should be given the opportunity to develop skills and participate in education that enables them to have a specific focus in their work. This specialisation enables staff to support their colleagues and be a source of knowledge within their team, leading to improved job satisfaction and wellbeing at work. This approach to career progression is particularly effective through innovative models of care.*¹¹³⁹

The QLS stated that increased and ongoing education and programs for staff in aged care and complementary hospital staff, such as discharge planners, social workers, geriatricians and others across the aged care sector will positively affect outcomes for residents, patients and staff.¹¹⁴⁰

Brisbane South PHN recommended that a workplace funded continuing education program should be mandatory 'as it is an important component in quality assurance and staff retention'.¹¹⁴¹

12.4.1.4 Attitudes as well as skills

A range of stakeholders called for the suitability of a potential aged care employee to be assessed, along with their education and experience.

Brisbane South PHN submitted that pre-service and continuing education should include adequate provision for screening the suitability of the workforce, as well as ongoing supervision and support, suggesting that attitudes, as well as knowledge and skills, should be assessed during recruitment to work in the aged care sector.¹¹⁴²

Woombye Care similarly submitted that few training organisations make sure their students are suitable to work in aged care, stating 'The RTO's are happy to take the money and give the certificate even if the person is not suitable for the job or hasn't properly achieved the competency they need'.¹¹⁴³

HammondCare also called for a greater focus on recruiting prospective employees on the basis of attitude and character rather than solely qualifications and experience, suggesting that it will further improve the quality of staff across the aged care sector.¹¹⁴⁴

Mr Michael Perritt submitted:

Training and selection of care professionals is of paramount importance to each individual and community member as we grow older. I have had cause to work in many Aged Care facilities throughout the last almost 40 years. On some occasions, I have seen care workers treating patients unfairly, without empathy and/or respect for those individuals and giving recognition to them for the many years they themselves, (the patients) have given to the community now caring for them. I would hope that this inquiry would see the importance of assuring that any current

¹¹³⁸ Submission 1301, p 6.

¹¹³⁹ Submission 1261, p 6.

¹¹⁴⁰ Submission 1201, p 9.

¹¹⁴¹ Submission 1212, p 4.

¹¹⁴² Submission 1212, p 4.

¹¹⁴³ Submission 1254, p 2.

¹¹⁴⁴ Submission 1261, p 6.

*or future carer within our country would be trained to the highest possible degree of competence prior to being engaged in the workforce as a carer or health professional.*¹¹⁴⁵

Queensland PHNs also suggested that recruitment should include adequate screening of the suitability of the workforce with a strong focus on attitudes and mind sets, as well as knowledge and skills.¹¹⁴⁶

Ms Tanya Battel told the committee that carers need to consider their role as more than a job, submitting:

*I hear over and over again that the standard of “carers” within nursing homes is simply not good enough. They are there for the purpose of it being a “job”. The role of a “carer” has to include qualities such as expertise in caring, it requires compassion and patience. It is not acceptable to have carers responsible for caring for our aged population who really don’t care. It is not acceptable for our aged population to lie in bed waiting hours to be attended to.*¹¹⁴⁷

Ms Rosemary Cosgriff suggested to improve aged care:

*... we must improve the training, the numbers of staff and the types of people we put in aged care. We cannot just put people there because they cannot get a job anywhere else or because the facility might get a \$20,000 bonus if they take a long-term unemployed person. Those have a really negative impact on the care.*¹¹⁴⁸

Dr S D’Urso similarly submitted that day-to-day workers should be selected on personal and training criteria to avoid exploitation of cheap labour.¹¹⁴⁹

Ms Sharon Tregoning advised that aged care staff also need to be supported in their role to be compassionate. She submitted:

More training is needed around strengthening resilience to reduce both burnout and desensitisation.

Last year, I commenced delivering training around strengthening resilience for care and health professionals serving people at the end of their life. It became very apparent quite quickly that not all professionals are supported in this area. One nurse shared with me her experiences of caring for a patient over a six year period. When this gentleman died, she naturally shed some tears. Her manager told her to “build a bridge and get over it.” This is horrifying. We need compassionate care professionals, but they also need to be supported appropriately.

*Other aged care staff frequently shared stories of not being able to tell other residents that someone had died and the distress that caused them. This also says to the other residents that they will not be remembered, acknowledged or considered having been important when their time comes.*¹¹⁵⁰

The Upper Mt Gravatt Wishart Catholic Parish also suggested that the well-being of staff should be considered, stating ‘By nature of aged-care, staff can experience grief and loss due to residents’ death and therefore need a supportive working environment’.¹¹⁵¹

¹¹⁴⁵ Submission E190.

¹¹⁴⁶ Submission 1301, p 6.

¹¹⁴⁷ Submission 232, p 6.

¹¹⁴⁸ Public hearing transcript, Townsville, 29 May 2019, p 29.

¹¹⁴⁹ Submission 310, p 2.

¹¹⁵⁰ Submission 2660, p 2.

¹¹⁵¹ Submission 1309, p 1.

12.4.1.5 Call for PCWs to be regulated

The Australian College of Nursing and the QNMU called for unregulated health care workers to be regulated. The Australian College of Nursing called for the regulation of workers to:

*achieve nationally consistent nomenclature/titles, minimum educational and ongoing professional development requirements and standards for scope of practice. Ensuring such regulation will provide a level of safety for all Australians across all health care settings, particularly aged care settings, as well as for UHCWs and registered nurses (RNs) responsible for their supervision.*¹¹⁵²

The QNMU submitted:

While the declining number of RNs and ENs working in aged [c]are regulated via the Australian Health Practitioner Regulation Agency (AHPRA) framework and the Nursing and Midwifery Board of Australia (NMBA) which sets professional practice standards, the majority of aged care workers are unregulated. While many of these workers have undertaken relevant Certificate III and Certificate IV training, there is no legislative requirement for them to do so.

The recent report from the Aged Care Workforce Strategy Taskforce (2018) clearly identifies a range of training and educational deficiencies in this workforce that result in a mismatch between the rising care needs of older Australians and the vocational training system ostensibly preparing unregulated care workers to meet the care demands of the sector.

...

*While aged care facilities are not hospitals, it is the position of the QNMU that significant, and increasing, levels of clinical/health care takes place in aged care facilities due to the needs of residents in terms of their diagnoses, co-morbidities, medication requirements, level of frailty and dependence. It is important to point out while an older Australian is waiting for an aged care bed in a hospital they will be assessed for, and receive, significantly higher levels of care as a routine than they would when they finally receive their place in the aged care facility down the road from the hospital, despite their care needs not changing over the course of a short trip from one facility to the other.*¹¹⁵³

12.4.1.6 Aboriginal and Torres Strait Islander workforce

During a private session with representatives from Aboriginal and Torres Strait Islander health services and other organisations, the committee heard challenges faced by Aboriginal and Torres Strait Islander communities in providing aged care, end-of-life care and palliative care for their community members.

It was acknowledged that community members want to be involved in their families' aged care and end of life, but often don't know how and don't have the support to be able to. It was said that if families are given the skills to cope in the situation, then they will be able to 'step up'.¹¹⁵⁴

Stakeholders raised the importance of involving community members and equipping them with the resources and support to be able to care for their families and communities.

Reference was made to the 'Skilling Queenslanders for Work' program, which is a Queensland Government initiative that funds training and support for unemployed or underemployed people, with a focus on young people (including those in and transitioned from out-of-home care), Aboriginal and Torres Strait Islander people, people with disability, mature-age jobseekers, women re-entering the workforce, veterans and ex-service personnel, and people from culturally and linguistically diverse

¹¹⁵² Submission 1232, p 2.

¹¹⁵³ Submission 1213, pp16-18.

¹¹⁵⁴ Private hearing transcript, Cannon Hill, 31 October 2019, p 7.

backgrounds.¹¹⁵⁵ As part of the Skilling Queenslanders for Work initiative, individuals are provided with training and support to enter workforce industries such as aged care and other community services.

It was recommended that should be a focus on training members of the community to provide care and training for their community.

12.4.2 Ability to attract and retain staff

Woombye Care commented on the difficulties of attracting and retaining staff, submitting:

*A lot of places are struggling for appropriately skilled staff. You only need to look at the jobs that are always being advertised in the sector and the use of agency staff. Residents can't have appropriate continuity of care when the staff are always different. High turnover of staff or continual staffing changes causes higher risk of medication errors and incidents, resident deterioration not being recognised, neglect, residents being given incorrect food or fluid consistency etc.*¹¹⁵⁶

SVHA referred to difficulties with staff retention, advising:

Overall our experience is that the mix of highly skilled and job ready staff are difficult to retain in the aged care sector.

*Under the current funding framework, it can be difficult for an aged care facility to put in place a staffing mix model which meets the mix of resident needs.*¹¹⁵⁷

Brisbane South PHN similarly submitted:

*There is a need to address issues such as high workload and lack of training, support and incentives, which contribute to the high turnover of aged care staff, an increased reliance on temporary agency staff, a lack of continuity of patient care, and higher costs.*¹¹⁵⁸

The QLS suggested that low numbers of RNs in RACFs contributes to the retention rates of RNs, submitting:

*...as already stated, there is no regulated ratio of nurses to clients. Given that RNs are more qualified, and therefore more expensive than PCWs, the outcome in aged care facilities is insufficient numbers of RNs employed and available to improve care standards. This deficiency has a further flow on effect, impacting on the retention rates of RNs as a result of issues such as burn out.*¹¹⁵⁹

The LCAQD commented on its experience as a provider in small rural communities, where they advised they often experience significant challenges in the recruitment and retention of registered nurses and allied health practitioners. The Lutheran Church submitted:

In these locations we are unable to compete for the small numbers of available personnel, given the wages and conditions state-funded health services are able to offer. As a result we pay additional retention incentives or more expensive locum or agency rates. This further erodes our viability and sustainability in these smaller and isolated communities.

¹¹⁵⁵ Queensland Government, Skilling Queenslanders for Work, <https://desbt.qld.gov.au/training/training-careers/incentives/sqw>.

¹¹⁵⁶ Submission 1254, p 2.

¹¹⁵⁷ Submission 1280, pp 14-15

¹¹⁵⁸ Submission 1212, pp 3-4.

¹¹⁵⁹ Submission 1201, p 3.

*A potential solution is an integrated approach to care using a hub model, whereby staff can work across jurisdictions in rural and remote communities, in a shared arrangement between employers - creating opportunities for all to benefit from these limited pools of resources.*¹¹⁶⁰

CentaCareCQ also advised that in some areas, particularly the more rural areas, staffing levels are an issue because the supply of workers isn't keeping pace with demand, making it difficult to provide the services that clients need when they need them.¹¹⁶¹

LASA also referred to service providers in rural and remote areas facing challenges in workforce recruitment and retention, and expressed support for the investment in a skilled workforce in line with recommendations from the Aged Care Workforce Taskforce Strategy Report, *A Matter of Care*.¹¹⁶²

The undervaluing of aged care work was also seen as impacting on staff attraction and retention. For example, PCQ contended that undervaluing the work of caring for people in aged care impacts on staff retention, which then impacts on a facility being able to deliver quality palliative care.¹¹⁶³

Woombye Care also referred to a poor attitude towards aged care nursing, stating that people have a belief that you only work in it if you can't get a job in other sectors, such as hospitals.¹¹⁶⁴

To address this issue, SVHA called for better promotion of the aged care sector, submitting:

...the Australian aged care sector is not always viewed as an attractive industry for a career. Critical to the future workforce pipeline to meet need in the aged care services, is the promotion of the sector as a beneficial place to work, with well-supported training, standards, positive work culture and service delivery.

CentaCareCQ also recommended investing in the workforce, including investing in promoting the jobs which requires a strategic approach to attract people to work in the industry from every age and background.¹¹⁶⁵

The QNMU called for improved pay, conditions and job security to increase workforce attraction and retention.¹¹⁶⁶

12.4.3 Pay and conditions

Stakeholders called for improved pay and conditions to attract and retain staff, address issues such as high staff turnover and low job satisfaction, and to improve the standing of aged care as an employment option.

Churches of Christ advised that the salary discrepancy between the acute care and the aged care sector and the portrayal of aged care being seen as 'a poor second cousin to the acute sector' continues to have a negative effect on recruitment to the sector.¹¹⁶⁷

The QLS also referred to reports that RNs employed in aged care facilities are paid less than their counterparts in hospitals, which they stated '...is likely to increase turnover and serve as a disincentive to retention of experienced nursing staff'.¹¹⁶⁸

¹¹⁶⁰ Submission 1277, pp 5-6.

¹¹⁶¹ Submission 1297, p 2.

¹¹⁶² Submission 1283, p 5.

¹¹⁶³ Submission 1891, p 48.

¹¹⁶⁴ Submission 1254, p 2.

¹¹⁶⁵ Submission 1297, p 6.

¹¹⁶⁶ Submission 1213, p 24.

¹¹⁶⁷ Submission 1281, p 6.

¹¹⁶⁸ Submission 1201, p 3.

Ms Catherine Bourke added that low rates of pay for those working in the sector and increasing stress levels caused by inadequate staff numbers result in less job satisfaction.¹¹⁶⁹

Ms Jacqueline Williams advised that disparity in pay, superannuation and entitlements is an issue in workforce attraction and attrition in both residential and home care settings compared to Queensland Health funded positions.¹¹⁷⁰

Reverend Stefan Slucki suggested that an increase in wages helped by an increase in per capita funding of each resident by government would ease the pressure on providers to find staff, especially in regional areas.¹¹⁷¹

Ms Sandy Silabon stated that better pay for aged care workers and higher standards of training would improve all aspects across the industry, while Ms Denise Sheehan submitted that care workers deserve better pay rates and more training.¹¹⁷²

A number of stakeholders called for aged care nurses to be provided pay parity with registered nurses in other parts of the health sector, along with improvements to the pay awarded to other aged care workers.

For example, PCQ supported pay parity for registered nurses and the need for personal care workers to be paid appropriately for the work they do, while Brisbane South PHN similarly submitted:

*Parity of remuneration for nursing and other staff working in the aged care sector with their peers in other parts of the health sector is required to attract the best applicants for the positions and encourage staff retention.*¹¹⁷³

Ms Linda Mungomery suggested that staff 'at the coalface' should be paid more to attract better staff and administration staff should be paid less.¹¹⁷⁴

Stakeholders also recommended that working conditions be improved. For example, SVHA submitted that improving workforce conditions would help attract and retain a qualified and committed workforce and help address high staff turnover and heavy workloads.¹¹⁷⁵

Jacqueline Williams commented that insufficient staff, staff turnover and long hours that may not all be paid are leading to 'burning out'.¹¹⁷⁶

Queensland PHNs recommended that aged care move from a compliance mindset to a continuous quality improvement approach to improve workplace culture, submitting 'This requires leadership and commitment to creating a workplace culture, free from fear and potential retribution for both staff, visiting staff, consumers and their carers/families'.¹¹⁷⁷

Palliative Care Nurses Australia submitted that the aged care workforce needs to be better prepared to meet the aged-palliative care needs of older people who wish to die at home or within a RACF. To achieve this ideal, Palliative Care Nurses Australia stated the number of RNs will need to grow, especially as the proportion of community aged care RNs has decreased over time.¹¹⁷⁸

¹¹⁶⁹ Submission 1558, p 2.

¹¹⁷⁰ Submission E1693.

¹¹⁷¹ Submission 1680, p 3.

¹¹⁷² Submission E268; submission 1540, p 1.

¹¹⁷³ Submission 1891, p 48; submission 1212, pp 3-4.

¹¹⁷⁴ Submission 1370, p 3.

¹¹⁷⁵ Submission 1280, p 14.

¹¹⁷⁶ Submission E1693.

¹¹⁷⁷ Submission 1301, p 6.

¹¹⁷⁸ Submission 1305, p 5.

12.4.4 Ageing workforce

Stakeholders noted that the ageing of the workforce has implications on the supply of aged care workers into the future.

CentaCareCQ noted that the aged care workforce median age is higher than the general working population (median age 39), and submitted:

*Recruitment is already difficult in response to recent increases in demand. With the ageing population and the ageing workforce, it is unlikely that recruitment will become easier in the medium term. There is a particular shortage of male care workers...The demand for care workers is also projected to outstrip supply, and this will have flow on impact to the aged care workforce supply in coming years. Without serious investment in community care workforce, there will continue to be unmet demand in Queensland.*¹¹⁷⁹

CentaCareCQ stated 'To meet demand, there will need to be investment in promoting the roles in the community care industry, and strategies to attract, recruit and retain workers'.¹¹⁸⁰

Churches of Christ also commented on the importance of attracting and retaining staff due to the ageing of the workforce, submitting:

*The ability to attract and retain clinicians, particularly nurses into key senior roles will continue to be a challenge as we see a burgeoning in retirement from the sector of the baby boomer workforce.*¹¹⁸¹

Ms Jacqueline Williams specifically referred to the ageing workforce in home care, such as personal care workers who undertake the more strenuous physical tasks of personal care and domestic duties. She commented that 'Organisations who focus on staff wellness programs may find their workforce attrition and accidents/incidents reduce due to an improvement in their health and wellbeing; albeit still an ageing workforce'.¹¹⁸²

Committee comment

The efficacy of training provided to prospective aged care workers needs to be improved. To achieve this, the Australian Government will need to audit and review courses to ensure they are effective at producing graduates with the minimum skills and competencies required to work in the aged care industry.

Given the demands of working in aged care and the complex needs of clients in care, ongoing training and development should become a feature of the industry, as in other health fields. Given the important role of personal carers in aged care, certificate 3 level training should be considered as the minimum standard for the industry. For existing employees with certificate 2 qualifications, there should be recognition of experience on the job in lieu of undertaking additional training.

To make the aged care industry a viable, attractive proposition to prospective employees and to aid employers to retain staff, the minimum pay and conditions for workers in the industry should be raised to levels equivalent to similar workers in the health sector.

Given the projected demand for aged care, current staffing issues and the ageing workforce, the government should devise a strategy to recruit and train the future aged care workforce for Queensland. This should include specific training and recruitment for Aboriginal and Torres Strait Islander people to work in roles providing aged care and health care for their communities.

¹¹⁷⁹ Submission 1297, p 5.

¹¹⁸⁰ Submission 1297, p 4.

¹¹⁸¹ Submission 1281, p 6.

¹¹⁸² Submission E1693.

Recommendation 38 Audit of accredited aged care training courses

The committee recommends that the Australian Government ensure accredited training courses for aged care are producing graduates with the required skills and competencies to perform the tasks required of them.

Recommendation 39 Aged care staff training and development

The committee recommends that the Australian Government call on providers to promote a culture in the aged care industry of ongoing staff training and development.

Recommendation 40 Certificate 3 qualifications for personal carers

The committee recommends that the Australian Government consider requiring that training equivalent to Certificate 3 in aged care is mandatory for all personal care workers in the aged care sector. For existing employees with certificate 2 qualifications, there should be recognition of experience on the job in lieu of undertaking additional training.

Recommendation 41 Better pay and conditions for aged care workers

The committee recommends that the Australian Government raise the minimum pay and conditions of employment for personal carers, nurses, administrators and other workers in the aged care industry to levels equivalent to their peers in the health sectors.

Recommendation 42 Workforce strategy for aged care

The committee recommends that the Queensland Government, in conjunction with the Australian Government, unions representing aged care workers, peak bodies representing the aged care providers and training providers devise a strategy to recruit and train workers for Queensland's aged care providers to meet future staffing requirements, to meet the increasing aging population, and demand for services in Queensland.

13 Future approaches to aged care

Stakeholders made a range of comments on what the future of aged care should look like. Some stakeholders called for the future of aged care to take a person-centred approach that meets the needs of those being cared for. For example, in support of this approach, COTA Queensland submitted:

*COTA Queensland believes that aged care services in Queensland can continue to be improved through a person and relationship-centred approach that supports healthy ageing, wellness in all its forms (physical, mental, social, spiritual) and inclusion. Services must be designed around consumers' needs, not providers' needs. Person-centred care supports services in responding to the diverse needs of individual Queenslanders.*¹¹⁸³

...

*COTA Queensland advocates that a person-centred approach to aged care in a decentralised state requires equity of access, regardless of geography. Policy and planning decisions need to ensure that aged care services do not discriminate on the basis of geographical location. It is likely that communication technology will have an increasing role to play in ensuring equity of access, particularly through remote monitoring and video-conferenced consultations.*¹¹⁸⁴

Brisbane South PHN also stated that the aged care sector '...must move towards more person-centred, less fragmented models of care (recognising and including the role of family and friends), aligning with contemporary evidence based health care practices'.¹¹⁸⁵

The QLS addressed the need for change to suit the baby boomer generation's demands:

Care services will be driven by a 'rights focussed' cohort, unwilling to be passive and overlooked.

*This will drive a demand for responsive and adaptive high quality staff and facilities, and a true 'client-centred' care model will be sought. Service providers will need to be flexible in order to meet the demands of their clients and there will need to be significant investments in additional systems and infrastructure, such as technology and other accessibility and service mechanisms. We can expect that Wi-Fi will become mainstream in all RACFs, high quality food provided, and activities offered that are more tailored and relevant. There has been a significant shift from paternalism to autonomy through this generation, and there will be a demand for the recognition of continued independence.*¹¹⁸⁶

In their submission, SVHA advised that the rise of patient-centred care in health and aged care services design means future residents of aged care services will hold a range of ideas for what alternative models should be considered. They recommended that future models should take into consideration the voice of the resident and their families as part of the service design, and provided the following ideas for future models informed by their experiences of delivering aged care services in Queensland:

- *Use of different mix of health staff – important that health professionals other than medical specialists are provided with up skilling and training in areas such as aged care, gerontology, dementia management, pain management, wound care, continence management and other chronic diseases.*
- *In the future, nurse-led teams consisting of other allied health support are an option to consider. These teams could coordinate with local GPs and aged care services to help support individuals in their home care environment.*

¹¹⁸³ Submission 1304, p 4.

¹¹⁸⁴ Submission 1304, p 12.

¹¹⁸⁵ Submission 1212, p 6.

¹¹⁸⁶ Submission 1201, p 6.

- *Opportunity to establish wellness hubs – such hubs could act as a source of information and advice to families and friends of those experiencing the ageing or advancing special needs of a loved one. These hubs could help promote the use of technology, raise community awareness about care and support needs, and de-stigmatise the ageing process, especially for those individuals keen to remain in their home with support.*
- *Serving Aboriginal and Torres Strait Islander residents better - Funders and facilities should be sensitive to the needs of Aboriginal and Torres Strait Islander peoples and support alternatives to residential care, understanding the impact of trauma arising from re-institutionalisation. Recent AIHW data forecasts that by 2023, all remaining Stolen Generation survivors will be eligible for aged care. There is a need to support alternative and culturally appropriate care to those who experienced significant trauma in their childhood due to forcible removal, at their last stage of life.¹¹⁸⁷*

To achieve their recommendations, SVHA's sees the need to address the gap between aged care funding and resident's expectations through key priority areas, most of which have been suggested by stakeholders throughout the committee's inquiry:

- Information sharing – across systems – needs infrastructure investment, better integration, real-time discharging information, and access to hospital records. (e.g. the rolling out of Queensland's new EMR system presents an opportunity for this to occur). This will address many current challenges, including unavoidable admissions.
- Improve the mix of the aged care workforce - including trialling and funding mobile allied health and dental services to aged care facilities.
- Improve access to medical support - such as after hours and palliative care, in regional and remote settings.
- Improve access to pharmaceutical services.
- Support and fund regular education in dementia and palliative care for all staff - This could include funding pilots which train nurse practitioners with advanced skills in geriatrics and with prescribing rights to all aged care facilities, which would improve timely access to medical care, reduce unnecessary emergency department presentations, and improve follow up care.
- Increased use of nurse practitioners- the provision of palliative and wound care, particularly in regional areas, would also help.
- Embedding advance care planning into aged care facilities – both through public education of planning for your own future, and through education to providers of aged care facilities so people are given the opportunity to remain in place if they wish to have end of life care in their aged care facility.¹¹⁸⁸

In their submission, CentacareCQ commented that the desire to stay living at home rather than in a residential setting will lead to an increase in the complexity of home care work and drive demand for more allied health and nursing supports than what is currently in the mix for community care workforce. To meet this demand, CentaCareCQ argued that the mix of staff in home care will need to change significantly, in particular with increased representation from allied health and nursing staff, and more focus will be needed on how to successfully work when the 'workplace' is actually people's homes, not just for home care workers but for allied health and other health professionals.¹¹⁸⁹

¹¹⁸⁷ Submission 1280, pp 15-16.

¹¹⁸⁸ Submission 1280, p 16.

¹¹⁸⁹ Submission 1297, p 2, 6.

Unsurprisingly, the issue of funding was raised by a number of stakeholders. For example, LASA advised that the capacity of providers to deliver care is constrained by the resources that are available to them. LASA suggested the following solutions to the funding constraints:

- implement the Tune Review recommendations to increase consumer contributions for those who can afford to pay
- set a fair interest rate on unclaimed lump sum accommodation payments
- fast track home care for those with low-means
- support those on the home care queue to use their home equity
- commence integration of Commonwealth Home Support and Home Care Programs
- invest in research to build the foundation of long-term reform

Other measures to improve funding for aged care that involve significant additional public support:

- indexation correction for residential care
- targeted relief for regional and remote facilities
- boost to funding for behavioural and psychological symptoms of dementia introduce maximum wait times for home care
- maintain the real value of home care packages
- begin investing in a skilled workforce.¹¹⁹⁰

Brisbane South PHN stated that ‘Funding models need to be sufficient and support quality outcomes along with financial viability of the service entities (but not profit to shareholders at the expense of quality care)’.¹¹⁹¹

COTA Queensland called for the Queensland Government to extend its approach to caring for the aged beyond the aged and healthcare systems to include support for community services, housing, transport, financial security, information provision and social inclusion are all relevant to supporting adequate care for older Queenslanders.¹¹⁹² In its submission, COTA Queensland encouraged the Queensland Government to continue to advance its Age-Friendly Strategy and actions, and to ensure that people are engaged and supported in living - and dying - as well as possible, within their communities.¹¹⁹³

13.1 Technology

Stakeholders also identified the central role technology will likely play in lifting the standard of aged care. The benefits of technology identified by stakeholders included:

- improved monitoring of the health and wellbeing of care recipients, such as through accelerometers for responding to falls, remote tracking sensors, applications to measure pain levels of people who are unable to speak/verbalise their pain levels¹¹⁹⁴
- increased efficiencies in the delivery of services to consumers¹¹⁹⁵

¹¹⁹⁰ Submission 1283, p8.

¹¹⁹¹ Submission 1212, p 6.

¹¹⁹² Submission 1304, p 14.

¹¹⁹³ Submission 1304, p 5.

¹¹⁹⁴ Submission 1277, p 6; 1281, p 9; 1309, p 7.

¹¹⁹⁵ Submission 1309, p 7.

- means of supporting the workforce to administer care, such as robotics to deliver food and laundry within a RACF, to refocus staff time towards residents¹¹⁹⁶
- reduce social isolation and improve connectivity for older Australians¹¹⁹⁷
- ensuring equity of access to care for those living in rural or remote settings, such as teleconsultation¹¹⁹⁸
- provide access to telehealth,¹¹⁹⁹ and
- family access to real time resident information, such as activities of the day, wellbeing of residents.¹²⁰⁰

In its submission, LASA stated that it supports its members in exploring options for advances in technology and innovation through support of the Aged Care Industry Information Technology Council (ACIITC) and its own innovAGEING program. The innovAGEING program:

*coordinates a community of practice for age services innovators, showcases examples of innovation in our industry, and celebrates age services innovation through a national awards program. Open to all individuals and organisations, the aim of the network is to foster and promote innovative, consumer-centric solutions to meet the increasingly complex needs of older Australians.*¹²⁰¹

Both AMA Queensland and Brisbane South PHN called for telehealth options to be funded under the MBS.¹²⁰² AMA Queensland recommended the Commonwealth Government review item numbers under the MBS to support increased use of telehealth by RACFs because:

*Our members indicate that when telehealth is used, the difference in patient care is substantial; scripts can be dispensed to patients, assessments made and timely hospital referral actioned. A video-based app allows for collaborative consultation with patient and nursing staff and non-urgent procedures such as scans can be organised. Projects such as RADAR or GEDI are invaluable in hospital avoidance for RACF residents and helps to reduce burden on General Practitioners. Telehealth improves care to residents where they can be managed in their own environments as well as supporting RACF staff and may lead to the creation of new guidelines for management of patients in a non-hospital setting.*¹²⁰³

On the ability to provide health care remotely, Professor Colleen Cartwright referred to research which found that telehealth options are ‘very acceptable’ to most older people, including those who are frail and unwell and those who live in rural and remote areas of Australia, including older Aboriginal and Torres Strait Islander people. Professor Cartwright’s research also found that telehealth can provide remote access when on-the-ground services are difficult to find; carers can be provided with equipment and, through FaceTime or Zoom, be “walked through” setting up equipment, giving injections and be generally supported in the care they provide to terminally ill patients.¹²⁰⁴

Stakeholders also warned against the overreliance on technology to deliver care. The LCAQD noted that while new technology and mobility aids have potential benefit for residential aged care, home

¹¹⁹⁶ Submission 1281, p 9; 1309, p 7.

¹¹⁹⁷ Submission 1281, p 9

¹¹⁹⁸ Submission 1277, p 6; 1281, p 9

¹¹⁹⁹ See, for example, submissions 1212, 1233, 1280.

¹²⁰⁰ Submission 1281, p 9.

¹²⁰¹ Submission 1283, p 6.

¹²⁰² Submission 1212, p 6; submission 1233, p 6.

¹²⁰³ Submission 1233, p 6.

¹²⁰⁴ Submission 1224, p 2.

care and retirement living, 'there are some policy and operational frameworks required to ensure their optimal use without compromising personal autonomy, choice and dignity'.¹²⁰⁵

It was also cautioned that technology should not replace or been seen as a substitute for people providing individual care to suit the needs of older Queenslanders. National Seniors Australia submitted 'Technology will not replace the need for competent staff to perform day-to-day care activities but it will augment their work, hopefully increasing efficiency and quality of care'.¹²⁰⁶

Similarly, the QLS stated:

*Considerable investments in new and ongoing technology are required but should be carefully implemented so as not to be achieved at the loss of individual care, as reliance solely upon a technologically-based solution runs the risk of increasing isolation and risk of abuse to vulnerable older people. Additionally, a greater focus on provision of services such as adequate palliative care, staff training, investment and development will be required.*¹²⁰⁷

The QNMU advised that because, in their view, a significant level of health care takes place in the aged care sector, particularly in the residential setting, innovation should be focused on the needs of the resident client, improve the safety and quality of care, enhance the capacity of care givers to provide care, and is planned, introduced and evaluated in a deliberate, evidence based way.¹²⁰⁸

However, the QNMU expressed concern that technology is often seen as a substitute for people. They stated:

Staffing and skill-mix levels are already woefully inadequate in the aged care sector and calls to substitute technology for evidence based levels of appropriately qualified and remunerated staff must be resisted as there are no simple solutions to the complex, interrelated and endemic issues of a sector now at crisis point.

*The QNMU believes the aged care sector significantly lags the acute sector in relation to clinical governance, quality and the development of a safety culture. When implemented appropriately, technology can support better governance, quality and safety. For example, electronic resident record systems can overcome some of the data sharing and exchange issues with other sectors such as hospitals and primary care that are often identified. Medication management systems can drive quality use of medicines practices and medication safety in a sector where many residents/clients have complex medical issues and medication histories and polypharmacy. The QNMU reiterates the same standards must apply across sectors. Simply receiving aged care services must not be an excuse to receive a lesser standard of care or reduced vigilance than other health care sectors.*¹²⁰⁹

Brisbane South PHN called for the National Residential Medication Chart to be moved from a paper based system to a more modern and efficient electronic system linking medical practitioners, pharmacists and the aged care facility. Their submission also notes that the present paper-based system is prone to clinical risk, medication errors and inefficiencies.¹²¹⁰

Brisbane South PHN also stated that it would be 'very beneficial to have visibility over the My Health Record, My Aged Care and potentially NDIS records through linkages'.¹²¹¹ Similarly, the AMA Queensland called for the Commonwealth Government to work with RACFs to 'develop a streamlined

¹²⁰⁵ Submission 1277, p 6.

¹²⁰⁶ Submission 1309, p 7.

¹²⁰⁷ Submission 1201, pp 8-9.

¹²⁰⁸ Submission 1213, p 25.

¹²⁰⁹ Submission 1213, p 25.

¹²¹⁰ Submission 1212, p 6.

¹²¹¹ Submission 1212, p 6.

electronic documentation system which enables service providers (including General Practitioners) to access patient's records'.¹²¹²

Ms Erika Gerdson also called for improved information sharing to assist those navigating the aged care sector. She submitted:

*I would like to think there would be better streamlining of services and improved information-sharing between services. It's really annoying, time-consuming and frustrating to have to sit through a fresh "intake" process every time a person starts with another hospital/health facility/service provider. Given that My Aged Care is often the central approval gateway, why can't the relevant information be stored/accessed there for everyone to see? It get[s] really tiresome to have to go over things again, and again, and again.*¹²¹³

A report prepared for the Royal Commission reviewed innovative models of aged care that operate in Australia and around the world.¹²¹⁴ The table below presents the examples of innovative models of residential care highlighted in that report.¹²¹⁵

Table 18: Innovative models of residential care

Residential aged care models	Key features
Small-scale living	Relationship- and person-centred approach to care. Emphasis on creating homelike living spaces, typically with 6–16 residents per house, where resident autonomy and independence is promoted and fostered. Can be dementia-specific or general aged care. Often involves 'culture change' and empowerment of care workers, with increased responsibilities for providing holistic care.
Community-based shared housing arrangements	Apartment-style or single-family home, small-scale living, with 6–8 residents per home, often in an urban setting. Emphasis on connection to neighbourhood and resident autonomy. Care provided by care workers and family members. Can be dementia-specific or general aged care.
Dementia villages	Community living for people with dementia, where 24-hour nursing care is provided, with 6–7 residents per house, plus communal shops and gardens. Safe environment where residents can participate in everyday activities within a village setting, with services operated by trained staff.
Additional complex supports for advanced dementia care	Multisensory program: Care for people with advanced dementia and end-of-life care. Creating a calm environment and unhurried loving approach to activity and interaction, pain management and hydration.
	Care coordination: Model of support, case coordinator and advanced dementia specialist team to help people with dementia live in comfort and with choice.
	Community of practice: International sharing of experiential learning and education of practitioners using virtual platform to allow a reiterative approach to best practice for advanced dementia care.
Intergenerational communities	Elderly residents needing care reside alongside members of the general public. Emphasis on resident interaction with children, students and/or other members of the community. Can be dementia-specific or general aged care.
Teaching nursing homes	Residential aged care homes designed to establish partnerships between the aged care and education sectors, provide education and training to the aged care workforce, promote aged care research and development and best-practice clinical care.

Source: Flinders University et al, *Review of Innovative Models of Aged Care*.

¹²¹² Submission 1233, p 6.

¹²¹³ Submission 1642, p 6.

¹²¹⁴ Flinders University, Bolton Clarke Research Institute, SAHMRI and Stand Out Report, *Review Of Innovative Models Of Aged Care*, Report prepared for the Royal Commission into Aged Care Quality and Safety, November 2019, <https://agedcare.royalcommission.gov.au/publications/Documents/research-paper-3-review-innovative-models-of-aged-care.pdf>.

¹²¹⁵ Flinders University et al, *Review Of Innovative Models Of Aged Care*, p 13, <https://agedcare.royalcommission.gov.au/publications/Documents/research-paper-3-review-innovative-models-of-aged-care.pdf>.

The table below presents examples of innovative models of community care from the same report.

Table 19: Innovative models of community care

Model type	Key features
Innovative models of respite	Community engaged scholarship: University students participate in structured sessions with older people as part of placement.
	Social and/or community integration: Collaborations developed with existing community services and centres, drawing on existing resources to supplement programs.
	Social and care farming: Services that have been adapted from a farm setting, using farm resources to promote health. Use of commercial farms and agriculture to promote physical and mental health, by partaking in normal farming activities. Supervised, structured program of farming-related activities.
	Cottage & home like respite: Provision of overnight (or day) respite care in a dedicated cottage home (purpose built or family home conversion).
	Adult placement: An adult who needs support/accommodation is supported in the home of others.
	Day centre: respite programs for day placement co-located in a residential care home.
Innovative support worker models	Integrated care: Management and delivery of services to ensure a continuum of care, according to needs over time and across different levels of the system.
	Care coordination: Using care coordinators or care managers to facilitate a streamlined approach to care.
	Case management: A collaborative process of assessment, planning, facilitation and advocacy for care and service options to meet holistic individual needs.
	Collaborative care: Working in collaboration with disciplines/other services outside of usual scope of practice.
	Coordinator and navigator: Relationship-centred care with enablement approach. Holistic and accessible. The role involves referral, linkage to, and navigation of, services; education and information provision; emotional and practical support; and advocacy.
	Workforce optimisation: Utilising and upskilling non-clinical or less qualified staff for roles that extend their usual scope of practice.
Dyadic caregiver interventions for people with dementia	Personalised interventions for people with dementia and their caregiver. Tailored intervention based on capabilities of the person with dementia (reablement focus; strengths-based approach) while also addressing concerns of carers via problem solving and skill building.
Other community-based approaches	Age-friendly cities and communities: Communities that enable people of all ages to actively participate in community activities. Everyone is treated with respect, regardless of their age. Communities that make it easy for older people to stay connected to people that are important to them, help them stay healthy and active, and provide appropriate support to those who can no longer look after themselves.
	Senior-friendly community living: Arrangements allowing individuals to age in place whilst remaining integrated within the community, supported by appropriate services or individuals.
	Asset-based community development: Emphasises people's and communities' assets, together with their needs. Taps into the wealth of resources, capabilities and networks that are inherent in communities. Connects people with supports that are more appropriately provided by the voluntary, community and social enterprise sectors.
	Autonomous team working: Geographically or 'neighbourhood' based working; small, autonomous or self-managed teams.

Source: Flinders University et al, Review Of Innovative Models Of Aged Care.

The report also highlighted innovative models of care for Aboriginal and Torres Strait Islander people. The following three examples of innovative approaches are from the report:

- Tjilpi Pampaku Ngura Aged Care Facility — This is the only residential aged care facility in the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands, located in the Pukatja (Ernabella) community, in northern South Australia, approximately 450 km from Alice Springs. The program is operated by an Aboriginal Community Controlled Health Organisation, within the Nganampa Health Council, rather than an aged care provider. It provides culturally appropriate respite and permanent care to the local community and other older Anangu people from APY communities.
- Bidyadanga Dementia Support Pilot — This started in 2016 as a result of a partnership between Alzheimer's Western Australia, Bidyadanga Community Council and Kimberley Aged Care Services. It provides person-centred care tailored to the specific cultural needs of older people living with dementia so they can stay in their community. Educating communities through presentations and workshops to increase dementia literacy is a key feature of the program. An innovation in delivering care from the program includes the creation of a personalised box for each resident filled with special objects, music and stories of the person's choosing. Residents can take this box with them should they need to leave their community to go to hospital or residential aged care, to help make them feel more comfortable in unfamiliar surroundings.
- Lungurra Ngoora Pilot — This is a culturally appropriate model of community care developed for frail older people, extended to others with physical disabilities and mental health problems, developed in consultation with older people, their families and carers, as well as community members and stakeholders. The model was implemented and evaluated in Western Australia over a period of 12 months. This locally designed, collaborative community service model led to a significant increase in services available as well as community knowledge about health service delivery. After one year, the program was ceased due to limited-term funding.¹²¹⁶

In considering how technology can support aged care, the *Review Of Innovative Models Of Aged Care* report noted that technology:

...traditionally provides additional capabilities to those supplied by human carers. These types of technologies can be conceptualised according to four main areas of usage:

- assistive and supportive technologies
- monitoring devices and systems
- communications and connection technologies
- intelligent health information systems.¹²¹⁷

Some examples and explanations of each of these four types of technologies are provided below.¹²¹⁸

¹²¹⁶ Flinders University et al, *Review Of Innovative Models Of Aged Care*, p 25, <https://agedcare.royalcommission.gov.au/publications/Documents/research-paper-3-review-innovative-models-of-aged-care.pdf>.

¹²¹⁷ Flinders University et al, *Review Of Innovative Models Of Aged Care*, p 35, <https://agedcare.royalcommission.gov.au/publications/Documents/research-paper-3-review-innovative-models-of-aged-care.pdf>.

¹²¹⁸ Flinders University et al, *Review Of Innovative Models Of Aged Care*, pp 35-40, <https://agedcare.royalcommission.gov.au/publications/Documents/research-paper-3-review-innovative-models-of-aged-care.pdf>.

13.1.1 Assistive and supportive technologies -

Mobility and dexterity supports

Use of mobility assistive devices allows an individual access to their broader living environment, exercise and social participation. Sophisticated technologies incorporated into devices, such as walking sticks and wheelchairs, can include motion surfaces, limb supplementation and balance enhancement, and detection and prevention of falling.

Robotics

The possibility that routine home care activities to assist ageing in place could be conducted by a robotic assistant has become a popular view. The roles of robots that have been targeted include addressing social isolation, assisting people with functional limitations and performing helpful activities for daily living and management of certain diseases or health conditions.

13.1.2 Monitoring devices and systems

Sensors

Wearable monitoring devices can provide ageing support by collecting data and providing measurement and feedback on someone's health circumstances. The information collected may include aspects of healthy lifestyle habits, physiological status, and preventive practices to help people manage and maintain their condition. Accelerometry-based devices can measure limb movement as an indicator of physical activity and mobility. Other devices allow for prediction or detection of adverse circumstances by combining measurement of movement with physiological measures such as falling or cardiac situations.

13.1.2.1 Communications and connection technologies

Home telehealth

Telehealth services can offer a technology-based mechanism for supporting person-centred care and enabling new models of care. It involves delivery of care by remote clinicians through teleconsultations and teleprocedures. The ability to deliver remotely to the home, to residential aged care settings, to people with limited access to transport and those living in rural and remote locations is a major strength. This approach can also support chronic disease management in older people.

13.1.2.2 Intelligent health information systems

Health information and education

The trend for individuals seeking information about their health conditions to make use of internet sources has accelerated and in general has become an expectation in primary health care. People extending their knowledge of their health conditions and histories provides a lifelong mechanism for better engagement. For aged individuals and their immediate family and carers, the use of internet health information may be limited by computer literacy and educational levels.

Coordinated self-care and home care

Technology can support care delivered in non-clinical settings by a variety of carers in coordination, along with telehealth services and data-driven quality-of-care monitoring. This can assist in meeting three of four areas highlighted as needing policy attention in a recent report on health and care in ageing societies.

Committee comment

Regardless of the current challenges in aged care, the combination of innovative models of care and the development of technology have the potential to revolutionise the delivery of culturally appropriate aged care services in the future. The provision of greater choice and flexibility in how care is provided to a population of users who are more aware of their rights as consumers, more demanding and more independent is integral to what the future models of aged care need to be.

Part 2 – End-of-Life and Palliative Care

14 Introduction and overview

The committee's terms of reference required it to inquire into and report on the delivery of end-of-life and palliative care in Queensland. This included consideration of the outcomes of recent reviews such as Queensland Health's *Palliative Care Services Review*.

This chapter sets out introductory information such as definitions of end-of-life and palliative care and an overview of the delivery of palliative care services in Queensland.

14.1 Palliative care and end-of life care in Queensland

14.1.1 Definitions of palliative care

According to the World Health Organization (WHO), palliative care is:

*...an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*¹²¹⁹

The WHO further explained that palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.¹²²⁰

This WHO definition is referenced within the Australian Government's National Palliative Care Strategy (discussed later in this chapter), which has been endorsed by all Australian Health Ministers.¹²²¹

The Queensland Government in its publications on the subject has defined palliative care as:

...healthcare that focuses on improving the quality of life and quality of care for people with a life-limiting illness, as well as families. It includes: the prevention and relief of suffering; communication about goals of care; and the early identification, assessment and treatment of physical, psychological, emotional, social and spiritual symptoms. Palliative care does not aim to

¹²¹⁹ World Health Organization, *WHO Definition of Palliative Care*, <https://www.who.int/cancer/palliative/definition/en/>.

¹²²⁰ World Health Organization, *WHO Definition of Palliative Care*, <https://www.who.int/cancer/palliative/definition/en/>.

¹²²¹ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, p 2 and p 4.

*slow down or speed up the dying process. Rather, it helps people live as actively as possible until death by enhancing their quality of life.*¹²²²

Palliative Care Australia (PCA), the national peak body for palliative care, explained to the committee:

*Palliative care is not just the last few days of life. It is relevant to anyone with a life-limiting condition, including people with multiple chronic conditions, those still receiving curative treatment, for babies in the womb who are likely to have a short life and people intubated in intensive care who are unlikely to survive the extubation process. Death does not automatically equal suffering, pain and fear. Death is not something that society should avoid until it touches them or a loved one. Death is something that we need to prepare for. Death is something that everyone in this room, every Queenslanders and each one of your constituents will need to experience one day. Death is simply a part of life. ... Palliative care does not rob people of time; it allows them to refocus their goals and conserve their energy so that they do have time for the things that matter most, instead of using that precious time to attend medical appointments and tests, and spending their superannuation on treatments that are highly unlikely to be effective.*¹²²³

14.1.2 Definitions of end-of-life care

While often used interchangeably with ‘palliative care’, the term ‘end-of-life care’ refers to palliative care that:

*...may be provided to anyone who is dying and refers to the care provided in the last few weeks of life in which a patient is rapidly approaching death. Complex end-of-life care is a component of specialist palliative care. Where the term ‘end-of-life care’ is used in relation to a patient who is receiving palliative care, it refers to the phase of palliative care in which increased services and support are essential to ensure that quality, coordinated care from the healthcare team is being delivered. This takes into account the terminal phase, or when the patient is recognised as imminently dying, death and extends to bereavement care.*¹²²⁴

Palliative Care Queensland (PCQ) stated in their submission that:

*...there is a significant difference between the provision of palliative care and just care at the end of life. Palliative care is for people who have a serious illness that is unlikely to be cured. Care may be ongoing for many months or years, delivered concurrently with other treatments and is focused on helping people live their lives as fully and comfortably as possible until death and to help families cope throughout the illness and in their bereavement. Care at the end of life or ‘end-of-life care’ represents a specific time frame, which varies and is unclear within the health sector. End-of-life care is sometimes referred to as 12 months, sometimes 6 months and sometimes the last few days of life. End-of-life care narrows the focus to the dying phase, often allowing opportunities for earlier support to be overlooked.*¹²²⁵

14.2 The Roles of State and Commonwealth Governments

Responsibility for the delivery of palliative and end-of-life care in Australia is shared between the Australian and state/territory governments. This reflects the various settings in which palliative care services are provided and their respective funding arrangements.¹²²⁶

¹²²² Queensland Government, *Palliative Care*, <https://www.qld.gov.au/health/support/end-of-life/care/palliative>.

¹²²³ Shyla Mills, Chief Executive Officer, Private briefing transcript, Brisbane, 23 January 2019, p 17.

¹²²⁴ Kathleen Forrester, Deputy Director-General, Strategy, Policy and Planning Division, Department of Health Private briefing transcript, Brisbane, 6 December 2018, p 2.

¹²²⁵ Submission 1891, p 3.

¹²²⁶ Queensland Health, correspondence dated 6 December 2018, p 10.

Under the *National Health Reform Agreement*, the states and territories are the system managers of the public hospital system, whilst the Australian Government has full funding and program responsibility for aged care and lead responsibility for general practitioner (GP) and primary care.¹²²⁷ Therefore, in relation to palliative care services in Queensland:

- *The Australian Government has responsibility for funding palliative care through general practice and Residential Aged Care Facilities (RACFs).*
- *The Australian Government and Queensland Government jointly fund palliative care through public hospital funding, with the Queensland Government being responsible for the delivery of specialist public palliative care services, including community palliative care, inpatient and outpatient services, and providing support to primary health care providers.*¹²²⁸

This results in a complex funding, policy and delivery framework for palliative care. As acknowledged by Queensland Health, ‘the challenge for both governments is to deliver person-centred models of care that overcome the policy and funding barriers and result in good patient outcomes’.¹²²⁹

14.2.1 Providers of palliative care – an overview

Palliative care is provided by a network of GPs, specialist palliative care physicians, other medical specialists such as oncologists and geriatricians, nurse practitioners, nurses, allied health professionals, counsellors, pastoral carers, family members and others.

Palliative Care Queensland highlighted:

...the supportive networks that surround an individual who has a diagnosis of a life-limiting condition, right up to the moment when they die...

*That is palliative care. Those supportive networks are made up of family, friends, work colleagues, neighbours and club members, as well as community and health supports. That is palliative care. As highlighted by Palliative Care Australia, palliative care is everybody's business.*¹²³⁰

14.2.1.1 Specialist palliative care services in Queensland

Specialist palliative care services are defined in the National Palliative Care Strategy as:

*Services provided by clinicians who have advanced training in palliative care. The role of specialist palliative care services includes providing direct care to patients with complex palliative care needs, and providing consultation services to support, advise and educate non-specialist clinicians who are providing palliative care.*¹²³¹

It is important to note that not everyone who dies requires palliative care. Dr Bill Lukin, Consultant, Community Palliative Care Services, Metro North Hospital and Health Service, explained:

*If you take a hundred people who are dying, most of those people do not need specialist care. Nearly a half of them die in hospital, nearly half die in residential aged care and then a smaller proportion die at home and in emergency departments. ... Every person who dies does not need a specialist palliative care physician and/or specialist palliative care nurses.*¹²³²

¹²²⁷ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 8, https://www.health.qld.gov.au/__data/assets/pdf_file/0025/852622/palliative-care-services-review-key-findings.pdf.

¹²²⁸ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 8.

¹²²⁹ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 8.

¹²³⁰ Private briefing transcript, Brisbane, 23 January 2019, pp 16-17.

¹²³¹ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, p 30.

¹²³² Private briefing transcript, 6 December 2018, p 3.

14.2.1.2 *Spiritual care*

Spiritual care is an integral part of palliative care.¹²³³ A number of submitters and witnesses to the inquiry highlighted the importance of spiritual care as a component of the provision of palliative care.¹²³⁴

A more detailed discussion of this can be found at 15.4 and discussion of the palliative care workforce in Queensland is contained in Chapter 17.

14.2.2 Settings for palliative care services

Palliative care services can be delivered wherever they are needed including a patient's home, a GP's surgery, community health facility or a hospital. The National Palliative Care Strategy states:

*In the last few decades, palliative care has become available within almost every healthcare setting, including neonatal units, paediatric services, general practices, residential aged care facilities, acute hospitals, and generalist community services. Palliative care is also provided through specialist palliative care services which operate from a variety of settings, including specialist inpatient consulting services, specialist inpatient settings, hospices and community-based specialist services. Care is also provided in the home, often by carers supported by home-based outreach services from public, private or not-for-profit agencies.*¹²³⁵

The Queensland Nurses and Midwives Union confirmed that this is what happens in Queensland:

*Like other jurisdictions in Australia palliative care services in Queensland are provided by public and private hospitals, dedicated public and private palliative care services, charities and hospice services, and aged care providers in the community and in residential aged care settings.*¹²³⁶

14.2.3 Hospices – private providers of palliative care and end-of-life care

Hospices play an important frontline role in the delivery of palliative and end-of-life care. A hospice is a facility that provides inpatient, residential care to relieve symptoms and support patients with an advanced terminal condition using an interdisciplinary approach to the provision of medical care, pain management and emotional and spiritual support. Queensland has a small number of hospices run by non-government organisations with some providing inpatient and home care and others providing home care only.¹²³⁷

A more detailed discussion of the settings for palliative care services in Queensland is provided in Chapter 15.

14.3 Previous reviews of palliative care and end-of-life care

In recent years, a number of reviews have been undertaken at state and national levels to evaluate and improve the delivery of palliative care services in Australia. This chapter discusses the recommendations of these reviews.

14.3.1 Senate Community Affairs Reference Committee 2012

The Senate Community Affairs Reference Committee inquired into the provision of palliative care in Australia including: the factors influencing access to and choice of appropriate palliative care that

¹²³³ Palliative Care Australia and Meaningful Ageing Australia, Joint Position Statement, *Spiritual Care: Integral to Palliative Care in Aged Care*, May 2017, <https://meaningfulageing.org.au/wp-content/uploads/2017/05/Spiritual-Care-Palliative-Care-Joint-Position-Statement.pdf>.

¹²³⁴ See, for example, submissions 1229, 1268, 1281, 1282.

¹²³⁵ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, p 7.

¹²³⁶ Submission 1213, p 27.

¹²³⁷ Queensland Health, *Queensland Health Palliative Care Service Review: Initial Outcomes*, p 2, https://www.health.qld.gov.au/__data/assets/pdf_file/0037/848359/palliative-care-services-review.pdf.

meets the needs of the population; funding arrangements; the efficient use of palliative, health and aged care resources; the effectiveness of a range of palliative care arrangements; the composition of the palliative care workforce; the adequacy of standards that apply to the provision of palliative care; advance care planning; and the availability of funding of research, information and data about palliative care needs in Australia. The report from that inquiry, 'Palliative care in Australia', tabled in October 2012 made 38 recommendations.¹²³⁸

14.3.2 Health and Community Services Committee 2013

In 2013, the Health and Community Services Committee of the 54th Queensland Parliament tabled a report titled 'Palliative and Community Care in Queensland: toward person-centred care'.¹²³⁹ The report argued that care should be centred around the person and be needs-based.¹²⁴⁰ When tabling the report, the Chair of the committee, Mr Trevor Ruthenberg MP, said:

*It was clear to the committee that current needs for palliative and community care services in Queensland are not being met and that the level of need is only going to increase. We believe though that elements of world-class palliative care are in place and can be built on to great effect and very efficiently.*¹²⁴¹

The report made 63 recommendations, covering a broad range of areas relating to palliative care. A number of the recommendations 'supported an approach to planning, funding and service delivery that would support greater focus on palliative care in the community'.¹²⁴² The then government, accepted 53 of these recommendations.¹²⁴³ Issues canvassed within the report included, but were not limited to:

- use of telehealth, eHealth and videoconferencing
- collection of palliative care data
- establishment of a children's hospice
- training (nurse practitioners, carers, ATSI, undergraduate pathways)
- funding (interpreters, separate palliative care from subacute funding, increased national funding)
- medication
- equipment loan services for home care
- education campaigns to increase awareness (burial assistance, palliative care options, advanced care planning), and
- development and implementation of a statewide palliative care strategy.¹²⁴⁴

¹²³⁸ Senate Community Affairs Reference Committee, 2012, *Palliative care in Australia*.

¹²³⁹ Queensland Parliament, Health and Community Services Committee, *Palliative and community care in Queensland: toward person-centred care*, May 2013, <https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2013/5413T2591.pdf>.

¹²⁴⁰ Queensland Parliament, Record of Proceedings, 23 May 2013, p 1777.

¹²⁴¹ Queensland Parliament, Record of Proceedings, 23 May 2013, p 1777.

¹²⁴² Queensland Parliament, Health and Community Services Committee, *Palliative and community care in Queensland: toward person-centred care*, May 2013, p xxi.

¹²⁴³ Queensland Health, correspondence dated 14 October 2019, p 1.

¹²⁴⁴ Queensland Parliament, Health and Community Services Committee, *Palliative and community care in Queensland: toward person-centred care*, May 2013, <https://www.parliament.qld.gov.au/Documents/TableOffice/TabledPapers/2013/5413T2591.pdf>.

Queensland Health provided the committee with an update in October 2019 on the progress against each of the 63 recommendations.¹²⁴⁵ Despite evidence of clear progress against the recommendations from the 2013 inquiry, many of the issues remain unresolved. In its submission to the inquiry, the Qld. Specialist Palliative Care Services Medical Directors' Group (QSPCSMDG) stated:

*It has been six years since the most recent inquiry into palliative care in Queensland. Little has changed. Overall the issues and recommendations from the previous inquiry continue to remain relevant and urgent.*¹²⁴⁶

14.3.3 Australian Government Productivity Commission 2017

Inquiry stakeholders referred to the 2017 Australian Government Productivity Commission report, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*.¹²⁴⁷ Chapter 4 of that report, *Caring for people at the end of life*, examined the provision of palliative care and end-of-life care in Australia. The report made five recommendations relating to the delivery of palliative and end-of-life care services including: increasing the availability of community-based palliative care; improving the quality of end-of-life care in residential aged care and ensuring clinical trained staff assist residents to develop or update an Advance Care Plan; promoting advance care planning in primary care; and, ensuring for cross-jurisdictional cooperation.

The Productivity Commission sent the report to the Australian Government on 27 October 2017, and the report was released publicly on 26 March 2018.¹²⁴⁸ At the time of writing, the Australian Government has not released its response to the report.¹²⁴⁹

14.3.4 Queensland Health Palliative Care Services Review 2019

The Queensland Health Palliative Care Services Review (Palliative Care Services Review) was a component of the department's End-of-life Strategy.¹²⁵⁰ According to the key findings from the review, the review's objectives were to identify current and future palliative care service needs, with a view to implementing a more person-centred, accessible and integrated system of palliative care in Queensland.¹²⁵¹

The Palliative Care Services Review considered the existing funding and delivery arrangements of palliative care services and demand trends impacting the delivery of those services. The review was completed in March 2019. It included environmental scanning, interjurisdictional and literature analysis, as well as input from a public and stakeholder consultation processes.¹²⁵²

The review identified five key areas of need:

¹²⁴⁵ Queensland Health, correspondence dated 14 October 2019, Appendix 1, <https://www.parliament.qld.gov.au/documents/committees/HCDSDFVPC/2018/AgedCareEOLPC/cor-14Oct2019-QH.pdf>.

¹²⁴⁶ Queensland Specialist Palliative Care Services Medical Directors' Group, submission 2681, p. 1.

¹²⁴⁷ Australian Government, Productivity Commission, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, October 2017, <https://www.pc.gov.au/inquiries/completed/human-services/reforms/report/human-services-reforms-overview.pdf>.

¹²⁴⁸ Australian Government, Productivity Commission, Human Services, <https://www.pc.gov.au/inquiries/completed/human-services>.

¹²⁴⁹ Australian Government, Productivity Commission, Human Services, <https://www.pc.gov.au/inquiries/completed/human-services>.

¹²⁵⁰ Queensland Health, correspondence dated 6 December 2018, p 10.

¹²⁵¹ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 6.

¹²⁵² Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 6.

- *Delivering high quality palliative care services that meet demand*
- *Supporting the palliative care sector workforce to deliver quality palliative care services*
- *Delivering better access to palliative care services that meets local needs*
- *Providing more education and information about palliative care services being delivered in Queensland, and*
- *Working with the Australian Government to advocate for the reform of national systems and processes to better support the delivery of palliative care services in Queensland.*¹²⁵³

The needs identified within the Palliative Care Services Review are broadly consistent with issues raised by stakeholders during the committee's inquiry.

The key findings report from the Palliative Care Services Review states that a key outcome of the review is the provision of additional funding of approximately \$10 million from 2019-20 to 2022-23 to the seven NGOs that deliver palliative care services.¹²⁵⁴

The review noted that this would assist in:

- *Increasing supply of clinical palliative care services*
- *Improving consumer choice in relation to community-based palliative care services*
- *Building the sustainability of the NGO service delivery sector.*¹²⁵⁵

¹²⁵³ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 32.

¹²⁵⁴ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 40; Queensland Health, correspondence dated 14 October 2019, p 3.

¹²⁵⁵ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 40.

15 Delivery and access

Palliative care and end-of-life care services are delivered by GPs, public and private hospitals, hospices, non-government and private sector organisations, residential aged care facilities, families and carers.¹²⁵⁶

This chapter examines strategies and the framework for delivering palliative care, the provision of palliative care and access to palliative care services.

15.1 The palliative care system: strategies, model and reporting framework

The Australian and the Queensland governments have developed strategies for the delivery of end-of-life and palliative care. These documents are outlined in the following sections, together with stakeholders' views on the sufficiency of those strategies.

15.1.1 National Palliative Care Strategy 2018

The Australian Government launched the first National Palliative Care Strategy in 2000, and released the revised *National Palliative Care Strategy 2010—Supporting Australians to Live Well at the end of Life* 10 years later.¹²⁵⁷

In February 2019, following extensive consultation and evaluation of the 2010 strategy, the Australian Government released the *National Palliative Care Strategy 2018* (the National Palliative Care Strategy).¹²⁵⁸ All Australian Health Ministers endorsed that strategy.¹²⁵⁹ The National Palliative Care Strategy provides a vision for palliative care 'that people affected by life-limiting illnesses get the care they need to live well'.¹²⁶⁰

The National Palliative Care Strategy sets out six guiding principles considered fundamental to the delivery of good palliative care. These are:

- *Palliative Care is person-centred care*
- *Death is recognised as a part of life*
- *Carers are valued and receive the support and information they need*
- *Care is accessible*
- *Everyone has a role to play in palliative care*
- *Care is high-quality and evidence-based.*¹²⁶¹

The National Palliative Care Strategy also identifies seven goals, expressed as a series of statements. These statements are listed in Table 13 below.

¹²⁵⁶ Queensland Health, correspondence dated 6 December 2018, p 9.

¹²⁵⁷ Australian Government, *Evaluation of the National Palliative Care Strategy 2010 Final Report*, p 2 -3, <https://www.health.gov.au/sites/default/files/evaluation-of-the-national-palliative-care-strategy-2010.pdf>.

¹²⁵⁸ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, <https://www.health.gov.au/sites/default/files/national-palliative-care-strategy-2018.pdf>.

¹²⁵⁹ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, p 2,

¹²⁶⁰ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, p 5.

¹²⁶¹ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, pp 10-11.

Table 20: National Palliative Care Strategy Goals

Goal	Description
Understanding	People understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care.
Capability	Knowledge and practice of palliative care is embedded in all care settings.
Access and choice	People affected by life-limiting illnesses receive care that matches their needs and preferences.
Collaboration	Everyone works together to create a consistent experience of palliative care across care settings
Investment	A skilled workforce and systems are in place to deliver palliative care in any setting.
Data and evidence	Robust national data and a strong research agenda strengthen and improve palliative care
Accountability	National governance of this Strategy drives action

Source: Australian Government, Department of Health, *National Palliative Care Strategy 2018*, pp 12, 14, 16, 18, 20, 22, 24.

The National Palliative Care Strategy states that implementation of the strategy will be guided by an implementation plan to be developed by Commonwealth, state and territory governments within the year following endorsement of the strategy. It also notes that a monitoring and evaluation plan will be developed to identify how progress on the priorities will be measured and reported.¹²⁶² At the time of writing this report, neither of those documents had been published.

15.1.2 Queensland Government's Statewide strategy for end-of-life care 2015

The Queensland Health *Statewide strategy for end-of-life care 2015*¹²⁶³ (the End-of-life Strategy) was developed in collaboration with Queensland clinicians and other key stakeholders.¹²⁶⁴ The strategy aims to 'strengthen the capacity of Queensland Health Services to respond to the needs of those with a progressive life-limiting illness' and 'deliver services that prioritise patient goals for quality of life as key components of care'.¹²⁶⁵

The End-of-life Strategy describes key service directions to guide planning and service development to meet future demand. These include:

1. *Knowledge of end-of-life care throughout public health organisations is expanded and includes a comprehensive awareness of the benefits in the planning and delivery of end-of-life care and availability of supporting services/resources within and between health services.*
2. *Earliest possible identification of patients who will or are anticipated to have shortened life expectancy as a result of known health conditions is routinely achieved, together with timely Advanced Care Planning (ACP) and the initiation of coordinated planning of end-of-life care.*
3. *End-of-life-care delivered in Queensland public services consistently responds to the needs of patients throughout their illnesses and meets established clinical safety and quality standards.*

¹²⁶² Australian Government, Department of Health, *National Palliative Care Strategy 2018*, pp 26-27.

¹²⁶³ Queensland Health, *Statewide strategy for end-of-life care 2015*, May 2015. https://www.health.qld.gov.au/__data/assets/pdf_file/0022/441616/end-of-life-strategy-full.pdf.

¹²⁶⁴ Queensland Health, correspondence dated 14 October 2019, p 3.

¹²⁶⁵ Queensland Government, Queensland Health, *End-of-life care strategy 2015*, <https://www.health.qld.gov.au/improvement/projects/end-of-life-care>.

4. *The strategic capability and configuration of end-of-life care services in Queensland is strengthened to maximise system health service delivery and performance so as to provide access to appropriate services for the projected population, while making the most effective use of available resources.*¹²⁶⁶

These overarching service directions are supported by a series of actions that include increasing public awareness of, and access to, Advance Care Planning, identifying and sharing best practice, and developing standardised assessment and management tools.¹²⁶⁷

The Care at End of Life Project Team within Queensland Health, established in 2016, coordinates implementation of the End-of-life Strategy in collaboration with HHSs. The project is governed by an Executive Governance Committee and is supported by a Statewide Reference Group with membership drawn from across the health sector.¹²⁶⁸

The department advised that the End-of-life Strategy was broader than a statewide palliative care strategy, which was recommended by the Health and Community Services Committee's 2013 inquiry:

*... the end-of-life strategy speaks to end-of-life care across a spectrum of clinical care, from a non-specialist palliative care approach through to general and then the more specialist end of palliative care. Developing a broader end-of-life strategy allows for the inclusion of advance care planning and other aspects of service delivery towards the end of life, with recognition that not all Queenslanders with a life-limiting condition have access to or indeed need access to specialist palliative care services.*¹²⁶⁹

15.1.3 The person-centred care model

The Australian & New Zealand Society for Geriatric Medicine defined person-centred care as:

*an approach to care in which health professionals and carers treat people the way they want to be treated and is recognised as a key component of developing high quality healthcare. Each person is treated as an individual with their own life story, culture, interests and beliefs with care being individualised to meet their own unique situation, needs and goals. Person-centred care means that we should respect the wishes of the individual, allowing them to make their own informed choices, and be flexible in meeting different needs for different people.*¹²⁷⁰

Person-centred care was the key focus of the former Queensland parliamentary Health and Community Services Committee's report into palliative care in 2013. Many of its recommendations carry this as a theme. The former committee stated:

The committee considers that Queensland should aim to deliver care that is the "right service, at the right place, at the right time". The aim is to deliver palliative care which is:

- *needs-based*
- *high quality, flexible and person-centred, sensitive to individual and cultural differences*
- *accessible to all and delivered in the home and community and across general and specialist areas of the health system, and*

¹²⁶⁶ Queensland Government, Queensland Health, End-of-life care strategy 2015, p v.

¹²⁶⁷ Queensland Health, correspondence dated 6 December 2018, p 10.

¹²⁶⁸ Queensland Health, Improving care at the end of life in Queensland, <https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/patient-safety/end-of-life/strategy>.

¹²⁶⁹ Professor Keith McNeil, Acting Deputy Director-General, Clinical Excellence Division, Queensland Health, public hearing transcript, Brisbane, 18 October 2019, p 11.

¹²⁷⁰ Australian & New Zealand Society for Geriatric Medicine, submission 1720. [In-text references have been removed. Refer to original source.]

- *provided early enough in a person's disease trajectory that care can be planned and person's quality of life is maximised.*

*To achieve this, the committee believes that there needs to be a shift to more care in the home and community, supported by consultancy–liaison services provided by specialist palliative care services. A number of the committee's recommendations support an approach to planning, funding and service delivery that would support greater focus on palliative care in the community. The committee recognises that this shift needs general practitioners (GPs) and other health providers to provide care using a palliative approach, supported by specialist consultancy, professional development and related services.*¹²⁷¹

A number of stakeholders reinforced the view that all models of care should be person centred with the medical, psychological, physical and cognitive needs of palliative patients being taken care of by person-centred care teams, while acknowledging the complexity of delivering this type of care.¹²⁷²

The AMA Queensland and PCQ commented that the main obstacle to efficiently delivering a person-centred model of palliative care is funding.¹²⁷³ Funding is discussed in more detail in Chapter 18.

15.1.4 The system of delivery

As outlined in section 1.2, the Australian Government has responsibility for delivering palliative care through general practice and primary care as well as palliative care in RACFs while the Queensland Government delivers palliative care through the public hospital system and various inpatient and outpatient services as well as community care.¹²⁷⁴

Queensland Health funds HHSs and non-government organisations to provide palliative care in a range of settings which include 'hospitals, hospices, community, state-operated residential aged care facilities and home settings'.¹²⁷⁵

Queensland Health conducts healthcare purchasing negotiations annually through service agreements with each of the state's 16 HHSs. These agreements outline the services that the department will purchase and how much will be paid for the provision of these services.¹²⁷⁶ In 2018-19, Queensland Health allocated \$105 million for the delivery of palliative care by HHSs.¹²⁷⁷ The HHSs then provide a number of specialist palliative care services including '...in-patient care in a designated bed,

¹²⁷¹ Queensland Parliament, Health and Community Services Committee, Report no. 22, *Palliative and community care in Queensland: towards person-centred care*, p xxi.

¹²⁷² See, for example, submissions E267, 1203, 1207, 1213, 1230, 1239, 1249, 1253, 1255, 1288, 1290, 1301, 1720, 2604. Ms Julie Crawshaw, public hearing transcript, Caloundra, 3 May 2019, p 31; Dr Robyn Brogan, Palliative Medicine Specialist, Townsville Hospital and Health Service; and Clinical Lead, Statewide Strategy for End of Life, public hearing transcript, Townsville, 29 May 2019, p 19; Dr Greg Parker, public hearing transcript, Brisbane, 5 April 2019, p 3; Mr Steve Williamson, Health Service Chief Executive, Central Queensland Hospital and Health Service; Adjunct Professor, CQ University, public hearing transcript, Rockhampton, 17 July 2019, p 2. Person-centred care can also be known as patient-centred, client led care, person driven care, individualised care, and consumer directed care: M Carlile, CEO Palliative Care South East, 'Is there such a thing as Person Centred Care?' 17 May 2018, <https://palliativecare.org.au/palliative-matters/is-there-such-a-thing-as-person-centred-care>.

¹²⁷³ PCQ, submission 1891; The University of Queensland, submission 1219; AMAQ, submission 1233, p 5.

¹²⁷⁴ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 8, https://www.health.qld.gov.au/__data/assets/pdf_file/0025/852622/palliative-care-services-review-key-findings.pdf.

¹²⁷⁵ Queensland Health, correspondence dated 6 December 2018, p 11.

¹²⁷⁶ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 21

¹²⁷⁷ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 21.

consultation liaison and outpatient services in acute hospital setting, and specialist palliative care advice and support to home and community based care'.¹²⁷⁸

In addition, Queensland Health provides funding to private providers of palliative care and hospice services outside of the HHSs through three separate funding paths.

Queensland Health provides grant funding to seven NGOs to deliver palliative care clinical services within the community, all located within South East Queensland:

- Cittamani Hospice Service
- Ipswich Hospice Care Inc
- Hopewell Hospice Services (now part of the Wesley Mission Queensland)
- Karuna Hospice Service
- Little Haven Cooloola / Sunshine Coast Palliative Care Association Inc
- St Vincent's Private Hospital; and
- Toowoomba Hospice Association Inc.¹²⁷⁹

These NGOs deliver a mix of home and community-based care and hospice-based care. Some provide a mix of services. As noted by Queensland Health's Palliative Care Services Review findings, there is wide variation in the services provided to clients. While all the organisations funded provide palliative care nursing, some also focus on respite, others psychosocial support and another offers medical support and support over the telephone.¹²⁸⁰

Under a contractual arrangement with Wesley Mission Queensland, Queensland Health and the Australian Government jointly fund Hummingbird House at Chermside in Brisbane; Queensland's only children's hospice.¹²⁸¹

The department provides further funding to three NGOs for a number of non-clinical palliative care services:

- Palliative Care Queensland – for information and community awareness services
- St Vincent's Private Hospital – Training Fellowship Program, and
- Cancer Council Queensland – 24 Hours State-wide palliative care helpline (PalAssist) and nurse counselling pilot.¹²⁸²

Funding arrangements are discussed further in Chapter 16 of this report.

15.1.5 Coordination in a fragmented system of delivery

Inquiry stakeholders noted that the palliative care service system is fragmented, resulting in challenges for patients, carers and even health professionals to navigate the system.¹²⁸³

At the public hearing in Caloundra, Dr Matthew Cooper, Palliative Care Advanced Trainee, St Vincent's Private Hospital Brisbane commented:

¹²⁷⁸ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 15.

¹²⁷⁹ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 19.

¹²⁸⁰ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 19.

¹²⁸¹ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 19.

¹²⁸² Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 19.

¹²⁸³ Grattan Institute submission 24, p 20.

*Across Queensland the funding and resourcing of community palliative care, the access to these resources and the workforce capacity to deliver care are not universally consistent or available. In a fragmented system this creates somewhat of a lottery as to the care people receive.*¹²⁸⁴

The Grattan Institute described the patient journey at the end of life as ‘disjointed and confusing for patients and their family’, particularly when patients are discharged from hospital into community care.¹²⁸⁵

Many noted the importance of coordination of care and called for improved coordination of services.¹²⁸⁶

Brisbane South Primary Health Network supported further integration of services across government and stated:

*In summary, we recognise the many challenges across state and federal health and aged-care systems in meeting the needs of older people of Queensland. We welcome an integrated and strength based planning approach that places the person at the centre and recognises the need for improved integration between health and the broader care needs of older people and those needing the support of palliative care services.*¹²⁸⁷

The Council on the Ageing Queensland acknowledged:

*It is about that integration with the healthcare system. This is where I think some of the issues arise. We have the federal government funding the aged-care system. We have the state government funding the hospital and health services. Often we have residents of aged-care facilities who are transported to hospital unnecessarily when in fact the residential aged-care facility is now their home. It is about how we coordinate and integrate those services.*¹²⁸⁸

Similarly the Anglican Church Southern Queensland called for a more integrated service provider model:

Bureaucratic red tape, for example, mires the path to palliative care for residents in regional Queensland towns, where the hospital provides a nurse practitioner who will pay limited visits to the local Anglicare aged care facility. But the Resident GP must document that they want their involvement in care, and the nurse practitioner is located in and employed by another aged care facility. There is no education component with this service and it is not advisory, with the nurse practitioner taking over pain management from the GP.

A more integrated service provider model is required to avoid situations for providers and patients where a split combination of cobbled-together funding from State and Commonwealth Governments is required to ensure a higher level of quality community in-home palliative care. Palliative care provision should be integrated and seamless for the patient/client, while minimising anxiety regarding how to leverage multiple health and aged care systems and programs to achieve a level of care. Our philosophy, holistic model of care and experience reinforces the fact that quality palliative care needs to also have as an integral part of the service,

¹²⁸⁴ Public hearing transcript, Caloundra, 3 May 2019, p 3.

¹²⁸⁵ Submission 24, p 20.

¹²⁸⁶ See, for example, submissions 24, 219, 1203, 1213; Ms Mary Quilty, public hearing transcript, Mount Isa, 31 May 2019, p 23.

¹²⁸⁷ Lucille Chalmers, General Manager Commissioned Programs, Brisbane South Primary Health Network, Brisbane, public hearing transcript, 4 July 2019, p 45.

¹²⁸⁸ Mr Mark Tucker-Evans, Queensland Chief Executive, Council of the Aging Queensland, Public hearing transcript, Brisbane, 13 September 2019, p 16.

*spiritual care which many Queenslanders currently miss out on due to the fact that spiritual care is unfunded.*¹²⁸⁹

Ms Anne Curtis, Engagement Consultant at Health Consumers Queensland, told the committee that the community members HCQ had consulted with made ‘multiple requests for the introduction of a nurse navigator role to support patients and families to navigate end-of-life and palliative care access, information, choices and support services’.¹²⁹⁰ It was suggested this role could improve navigation and service coordination for patients and their families.

Ms Curtis also conveyed views of community members who had raised concerns with lack of coordination between treating specialists of a palliative patient.¹²⁹¹ It was reported that family members perceived a lack of coordination which meant ‘patients with multiple specialists or care providers were receiving different information and treatment, resulting in confusion and distress’.¹²⁹²

A number of stakeholders suggested introduction of a statewide palliative care service delivery plan and/or strategy would improve integration and coordination of services.¹²⁹³

Ms Shyla Mills, Chief Executive Officer, Palliative Care Queensland, told the committee:

*There has been a lot of reform in palliative care over the past few years, mainly on the national front and also the international front, and this has been part of it. What we were saying is that at the state level we want to look at what the impact of all of this nationally and internationally means at the Queensland level, integrating the big picture down to the smaller picture of Queensland itself. New standards for palliative care came out last year and a new service delivery framework has come out. There is currently some discussion even internationally around the World Health Organization definition of palliative care. There is a lot happening in this space at the moment, so what we were calling for is really looking at bringing all of that into the Queensland model to work out the priorities for Queensland and where we need to shift things in a reform.*¹²⁹⁴

In its submission, PCQ recommended the development and implementation of:

*...a Queensland Palliative Care Strategy based on the National Palliative Care Strategy which links to the Statewide Strategy for End-of Life Care but includes specialist palliative care, generalist palliative care and public health palliative care. This strategy should include services delivered outside of Queensland Health (including Private, NGO services and community organisations) and should highlight the value of Specialist Palliative Care as the providers of leadership, clinical expertise and strategic input.*¹²⁹⁵

The Royal Australasian College of Physicians (RACP) advised that such a plan could serve as a central service delivery model and equitable population-based funding framework designed to remedy reported lack of care coordination across care settings and time, inconsistent models of care, ineffective funding and inequitable resource allocation models, workforce shortages and other issues related to poor integration and coordination across the sector.¹²⁹⁶

The QNMU stated:

¹²⁸⁹ Anglican Church Southern Queensland, submission 1229, p 9.

¹²⁹⁰ Public hearing transcript, Brisbane, 13 September 2019, p 23.

¹²⁹¹ Public hearing transcript, Brisbane, 13 September 2019, p 23.

¹²⁹² Public hearing transcript, Brisbane, 13 September 2019, p 23.

¹²⁹³ See, for example, submissions 1891, 1203.

¹²⁹⁴ Private briefing transcript, Brisbane, 23 January 2019, p 29.

¹²⁹⁵ Submission 1891, p 4.

¹²⁹⁶ Submission 1203, p 3.

...despite this report [2013 inquiry], the development of a statewide strategy for end-of-life care in 2015 and a Queensland health palliative care services review in 2018, these services remain inequitably distributed, under-resourced and poorly coordinated. Implementation of the 2015 plan is currently the responsibility of individual HHSs and we believe the devolved model of accountability has been an impediment to resolving the issues identified in this submission.

*Palliative and end-of-life care are critical and essential aspects of the health system that cannot be left to HHSs to implement in a patchwork and piecemeal approach. The QNMU believes implementation of statewide strategic plans must be the responsibility of Queensland Health so that previously identified issues of equity, funding, workforce planning, training and education, and integration with the aged care sector are achieved rather than being left to the insular and parochial decision making and vagaries of individual HHSs.*¹²⁹⁷

The QNMU recommended the department take overall responsibility for implementation of the End-of-life Strategy rather than relying on its implementation by individual HHSs:

*The QNMU believes the current devolved governance arrangements for health services are flawed and cannot be relied on to achieve a strategic approach to palliative and end-of-life care that is needed across the state.*¹²⁹⁸

Dr Stephen Duckett of the Grattan Institute outlined the importance of setting clear expectations for palliative care services, noting the government needed to express clear expectations and to provide clarity on what good practice looks like.¹²⁹⁹ Dr Duckett expressed caution at further development of plans, stating:

*The reason I am a bit cautious about saying, 'This is a plan' is that I am sick of plans that are written and then the government says, 'We've actually done a plan' and more or less implies that is all they have to do. I think we have to be careful about putting our eggs in a plan basket. Certainly, we need the government to have clear statements of expectations and clear statements about where we want to go with palliative care, but that is not enough. Behind that, we have to say to the HHSs, 'This is what you have to do and here is the money to do it'.*¹³⁰⁰

Dr Lee-Apostle, a palliative medicine specialist at the Toowoomba Hospital, highlighted the need for a statewide approach to palliative care to make access equitable and better resourced.¹³⁰¹ Dr Lee-Apostle stated that a statewide strategy was needed to address the challenge of different levels of care being available to a person in a metropolitan area versus somebody in a remote or regional area.¹³⁰² Dr Lee-Apostle highlighted the need for extensive consultation with all palliative care healthcare professionals to develop such a plan:

*...including people on the ground, people who are in remote areas where there are no community services available, despite the fact that we have funding for them—places where there are no GPs, or GPs who change every two weeks because they cannot get any permanent staff.*¹³⁰³

¹²⁹⁷ Submission 1213, p 33.

¹²⁹⁸ Submission 1213, p 34.

¹²⁹⁹ Public briefing transcript, Brisbane, 4 July 2019, p 32.

¹³⁰⁰ Dr Stephen Duckett, Director, Health Program, Grattan Institute, public hearing transcript, Brisbane, 23 August 2019, p 62.

¹³⁰¹ Dr Patricia Lee-Apostle, Palliative Medicine Specialist, Toowoomba Hospital, public hearing transcript, Toowoomba, 17 May 2019, p 2.

¹³⁰² Dr Patricia Lee-Apostle, Palliative Medicine Specialist, Toowoomba Hospital, public hearing transcript, Toowoomba, 17 May 2019, p 7.

¹³⁰³ Dr Patricia Lee-Apostle, Palliative Medicine Specialist, Toowoomba Hospital, public hearing transcript, Toowoomba, 17 May 2019, pp 7-8.

Mr Toby Hall, Group CEO of St Vincent's Health Australia stated:

*We believe that the inquiry provides an opportunity for Queensland to develop a whole-of-the-state, world-class end-of-life strategy. We advocate firstly for a master plan to coordinate care and support Queenslanders who are approaching the end of their life based on the following reforms: firstly, an opportunity to identify and address the many bureaucratic contractual, technological and funding issues and inconsistencies across aged-care and palliative care systems. This requires an all-of-government response to start working better to deliver an holistic integrated end-of-life care system for all Queenslanders.*¹³⁰⁴

Ms Carol Hope, State Council Member of PCQ, highlighted that within the department, there is more than one responsible division, and that:

...we do not have anybody within our Department of Health that singularly holds a portfolio of palliative care. It sits across what we understand to be three departments. It has been incredibly difficult to navigate that, because funding comes from one place, strategy comes from another and then we have the end-of-life project in another. These sit within different divisions of Queensland Health. I think one of the things moving forward for Queensland has to be that this comes into one place and that it is recognised as being an important part of what we do in health care and beyond.

...

*It needs a home. It is very difficult to navigate through that system. I understand the different functions of those departments, but that is where that one strategy comes into place where there is one source of truth.*¹³⁰⁵

It was noted that the HHSs in Queensland operate independently in how they deliver palliative care services. Ms Hope stated the PCQ's preference 'would be a single place within the system manager, which is the department, that would then provide that policy framework for HHSs to work within'.¹³⁰⁶

15.1.5.1 Role of palliative care nurse practitioners

The role of palliative care nurse practitioners in palliative care was highlighted by a number of stakeholders who outlined their importance to the coordination of care.

Queensland Primary Health Networks submitted:

*The evidence base shows that Palliative Care Nurse Practitioners add value by improving the coordination of care, achieving better integration with General Practitioners, specialists and allied health, supporting facility staff and improving communication, involvement and decision making of the resident and their families and carers.*¹³⁰⁷

St Vincent's Health Australia noted in particular that each cancer multidisciplinary team 'should have a Palliative Medicine Specialist and/or a Palliative Care Nurse as a core member of the team to ensure appropriate and timely referral and improved outcomes for patients and their families'.¹³⁰⁸

The QNMU reported on the benefits of nurse practitioner models of care, and submitted:

The National Evaluation of the Nurse Practitioner — Aged Care Models of Practice Initiative (Davey et al., 2015) found a range of positive outcomes from nurse practitioner models of care, which included:

¹³⁰⁴ Public hearing transcript, Brisbane, 4 July 2019, p 46.

¹³⁰⁵ Public hearing transcript, Brisbane, 4 July 2019, p 85.

¹³⁰⁶ Public hearing transcript, Brisbane, 4 July 2019, p 85.

¹³⁰⁷ Submission 1301, p 10.

¹³⁰⁸ Submission 1280, p 22.

- *improved access to primary care for older people though filling service gaps and supplementing general practitioner services;*
- *the provision of new and expanded services and the development of innovative delivery models;*
- *a range of models across sub-acute care, primary care and primary health;*
- *reduction in unnecessary hospitalisations;*
- *education and skill development for the aged care workforce;*
- *coordination of care.*¹³⁰⁹

The AMA also highlighted the role of registered nurses, noting they ‘form one of the most important roles as part of the multidisciplinary care team as they have the training, expertise and coordination skills needed to ensure the care required to be delivered is implemented’.¹³¹⁰

15.1.6 Performance reporting by palliative care services

The importance of transparent and accountable palliative care services was raised by a number of stakeholders.¹³¹¹ In particular, some stakeholders expressed concern that there are inadequate reporting mechanisms, for both service demand and performance outcomes of services.¹³¹²

Recommendations were made to improve transparency and accountability of palliative care services in Queensland.¹³¹³ These focussed on an increase in reporting, as well as further guidelines and specified requirements on expected performance measures of services.¹³¹⁴

Queensland Health’s Clinical Services Capability Framework applies to both public and private hospitals, and outlines ‘minimum requirements for the provision of health services in Queensland public and licensed private health facilities, including minimum service, workforce, support service, legislative and non-mandatory requirements and risk considerations’.¹³¹⁵

Dr Greg Parker commented on the self-reporting nature of the Clinical Services Capability Framework, noting: ‘At the moment it is self-reporting... There is a bits-and-pieces patchwork approach to delivering palliative care. I think we need to make the system accountable for that’.¹³¹⁶ Dr Parker suggested the framework is not being properly utilised.¹³¹⁷

Suggestions to improve performance of palliative care services included the introduction of key performance indicators (KPIs).

¹³⁰⁹ Submission 1213, p 21.

¹³¹⁰ Submission 1233, p 2.

¹³¹¹ For example, submission 24, 219; Ms Forward, public hearing transcript, Brisbane, 23 August 2019, p 55; Dr Good, public hearing transcript, Brisbane, 13 September 2019, p 43.

¹³¹² Dr Good, Public hearing transcript, Brisbane, 13 September 2019, p 43. Dr Stephen Duckett, Public hearing transcript, Brisbane 23 August 2019, p 60; Ms Hope, Public hearing transcript, 4 July 2019, p 85.

¹³¹³ Submission 1891, p 15; Dr Good, Public hearing transcript, Brisbane, 13 September 2019, p 43.

¹³¹⁴ Dr Phillip Good, Public hearing transcript, Brisbane, 5 April 2019, p 12; Dr Stephen Duckett, Public hearing transcript, Brisbane 23 August 2019, p 60-61; Dr Good, Public hearing transcript, Brisbane, 13 September 2019, p 43; Submission 1280, p 25; Grattan Institute submission 24, p 44-45; Submission 1891, p 16, 50.

¹³¹⁵ Department of Health, *About the CSCF*, <https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/service-delivery/cscf/about>.

¹³¹⁶ Public hearing transcript, Brisbane, 5 April 2019, p 13.

¹³¹⁷ Public hearing transcript, Brisbane, 5 April 2019, p 13.

Dr Phillip Good suggested ‘the key is to have accountable key performance indicators which are minimum standard for every HHS’.¹³¹⁸

The introduction of KPIs was also identified as a key priority by St Vincent’s Health Australia, which stated ‘All publicly and privately funded palliative care services should have clear KPIs to which they are accountable’.¹³¹⁹

It was suggested KPIs or other performance reporting by palliative care service providers could be tied to activity-based funding ‘with performance monitoring and make explicit use of performance metrics and reporting’.¹³²⁰

The Australian Association of Social Workers similarly supported introduction of Queensland ‘standards’ for palliative care services both in health and community settings.¹³²¹

Professor Patsy Yates outlined the existing data collection and reporting of the Palliative Care Outcomes Collaboration (PCOC). The PCOC is part of the Australian Health Services Research Institute (AHSRI), which is a research facility at the University of Wollongong.

The PCOC is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care.¹³²² Its ‘primary objective is to systematically improve patient outcomes’.¹³²³

The PCOC patient outcome improvement framework is designed to:

- provide clinicians with the tools to systematically assess individual patient experiences using validated clinical assessment tools
- define a common clinical language between palliative care providers to support assessment and care planning
- facilitate the routine collection of national palliative care data to drive quality improvement through reporting and benchmarking
- provide regular patient outcomes reports and workshops to facilitate service-to-service benchmarking, and
- support research using the PCOC longitudinal database.¹³²⁴

Professor Yates, Deputy Vice-Chancellor and Vice-President (Research and Innovation), Queensland University of Technology, outlined the important work of PCOC, stating:

*That is an important national program for specialist palliative care in the sense that it is around measuring and reporting outcomes. Part of that program has enabled us to understand what we are achieving and where there needs to be quality improvement. That program is about measuring outcomes on a routine basis, feeding that information back to service providers and helping them identify solutions to make some improvements.*¹³²⁵

¹³¹⁸ Public hearing transcript, Brisbane, 5 April 2019, p 12.

¹³¹⁹ Submission 1280, p 22.

¹³²⁰ Grattan Institute submission 24; PCQ submission 1891, p 16.

¹³²¹ Submission 1288, p 20.

¹³²² University of Wollongong, *What is PCOC*, <https://ahsri.uow.edu.au/pcoc/about/index.html>.

¹³²³ Palliative Care Outcomes Collaboration, *PCOC Annual Report 2018*, p 2.

¹³²⁴ University of Wollongong, *What is PCOC*, <https://ahsri.uow.edu.au/pcoc/about/index.html>.

¹³²⁵ Professor Patsy Yates, public hearing transcript, Brisbane, 5 July 2019, p 39.

It is noted that the PCOC reports outcomes of specialist services ‘against the benchmarks which the sector has set for itself around quality palliative care’.¹³²⁶ The PCOC’s Queensland Report for January to June 2019, included data from 32 services in Queensland.¹³²⁷

The department advised the committee that it is working with PCOC to ‘understand trends and areas where better outcomes can be delivered across our system’.¹³²⁸

15.2 The provision of palliative care services in Queensland

The following sections outline the demand and delivery of palliative services in Queensland. This is done through a variety of services such as primary care, specialist palliative care services, services provided in hospitals, hospices, in the home and in the community. It also provides information about the availability of after-hours access to palliative care services.

15.2.1 The demand for palliative care services

Queensland Health provided the committee with estimates for annual demand for palliative care (specialist and non-specialist care appropriate to the level of need) and separations:

- Using mortality data, it is estimated that between 41% and 76% of people living with life-limiting illness would require palliative care services
- Using prevalence data, it is estimated that between 51,000 to 71,000 of the total population [in Queensland], and between 52,000 and 57,000 people over 65 years old would require palliative care services
- Between 2,700 to 4,900 children in the Queensland population under 19 years old could require palliative care services
- Almost 83,000 outpatient clinic or telephone sessions held in 2017-18, and
- A projected demand for inpatient palliative care services of 13,300 separations per annum by 2026.¹³²⁹

Stakeholders raised concerns with the lack of data about palliative care service demand and unmet need for services.¹³³⁰

Dr Greg Parker noted the difficulty in predicting demand and the numbers of staff and services required to meet the demand, due to a lack of available data.¹³³¹ This creates difficulties in assessing how much resourcing is needed to improve the system.¹³³²

The department acknowledged difficulties in estimating demand for palliative care services in Queensland, stating:

In particular, current methods for estimation of palliative care demand do not distinguish between need for specialist and non-specialist palliative care services and there is no consensus

¹³²⁶ Professor Patsy Yates, public hearing transcript, Brisbane, 5 July 2019, p 43.

¹³²⁷ PCOC, Australian Health Services Research Institute, University of Wollongong, *Patient outcomes in Palliative Care – Results for Queensland, January to June 2019*, September 2019.

¹³²⁸ Professor Keith McNeil, Acting Deputy Director-General, Clinical Excellence, Division, Queensland Health, public hearing transcript, Brisbane, 18 October 2019, p 12.

¹³²⁹ Queensland Health, correspondence dated 23 January 2019, *Briefing on aged care, palliative care and legal documents relevant to end-of life care in Queensland*, p 21.

¹³³⁰ See, for example, public hearing transcript, Brisbane, 5 April 2019, p 3; Submission 24.

¹³³¹ Public hearing transcript, Brisbane, 5 April 2019, p 3.

¹³³² Public hearing transcript, Brisbane, 5 April 2019, p 3.

*regarding the patient population in Queensland who would benefit from palliative care services.*¹³³³

15.2.2 Providing palliative care in primary care

Dr Mathew Cooper, a GP working on the Sunshine Coast hinterland explained the role of the role of GPs in delivering palliative care services in the primary care sector:

*For most patients, their palliative care journey begins with their GP, presenting with a symptom or concern that ultimately leads to the diagnosis of a life-limiting illness. The needs that follow in terms of delivering optimal care are extensive. The competing needs of GPs and the time-poor environment of general practice make this all the more challenging. This care will require a truly multidisciplinary approach in meeting the physical, psychological, social and spiritual needs of patients, their families and loved ones. Unfortunately, the competency with which these needs are met will depend on where the patient lives, the GP's comfort and skill level with practising palliative care and the support network the GP can access.*¹³³⁴

The Palliative Care Services Review stated that a 'GP's role will vary depending on the needs of the patient and their carer or family'.¹³³⁵ These roles and responsibilities may include:

- *identifying patients' end-of-life needs*
- *advance care planning*
- *referrals to specialist palliative care services*
- *holistic symptom management and optimising quality of life including prescription of pain management medications*
- *supporting a person to die in their place of choice*
- *addressing the needs of family and significant others*
- *providing grief and bereavement care or referring specialists as needed*
- *supporting care workers in the community, including staff in RACFs*
- *commissioning services to support the person*
- *referring patients for Aged Care Assessment Team assessments as required, and*
- *coordinating with other health care providers such as specialists.*¹³³⁶

The Grattan Institute recommended the strengthening of the primary care sector to address a lack of palliative care services outside of hospitals. It proposed additional investment in generalist palliative care services for home, community and residential aged care settings, and focussed on the need to bring care to the patient, rather than bringing the patient to care.¹³³⁷

In its submission, Palliative Care Queensland raised the importance of having a palliative care model in Queensland that is available and accessible to everyone,¹³³⁸ and recommended:

¹³³³ Queensland Health, correspondence dated 23 January 2019, *Briefing on aged care, palliative care and legal documents relevant to end-of life care in Queensland*, p 22.

¹³³⁴ Public hearing transcript, Caloundra, 3 May 2019, p 3.

¹³³⁵ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 20.

¹³³⁶ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 20.

¹³³⁷ Grattan Institute, Submission 24, p 24.

¹³³⁸ See, for example, submission 1891, p 17.

*...that Level 1 or generalist palliative care, be available to everyone. This means that GPs, nurse practitioners, medical officers, allied health officers, RACF staff and staff in community based services should be familiar with the principles of palliative and end of life care. Moreover, this care should be safe and of high quality.*¹³³⁹

15.2.3 Providing specialist palliative care services

Specialist palliative care services (as defined in section 14.2.1.1) operate in a variety of settings, including specialist inpatient services, hospices and home-based and community-based services.¹³⁴⁰ Historically, the public health system has provided the majority of specialist palliative care in Queensland.¹³⁴¹

Specialist palliative care services provided by Queensland's HHSs include 'in patient care in a designated bed, consultation liaison and outpatient services in acute hospital setting, and specialist palliative care advice and support to home and community based care'.¹³⁴² A health professional referral is generally required for admission to specialist care services.¹³⁴³

Palliative Care Queensland stated that 'quality palliative care occurs when strong networks exist between specialist palliative care providers, generalist palliative care providers including general practitioners, and those working within aged care and disability care at all levels'.¹³⁴⁴

15.2.3.1 Specialist palliative care services—stakeholder concerns and suggestions

Some inquiry stakeholders called for increased access to specialist palliative care physicians and services.¹³⁴⁵ The committee was provided with unpublished estimates that in 2017, of 10,916 deaths which potentially required specialist palliative care services only 4,185 of those people received palliative care service, leaving a gap of 6,731 people (almost 60 percent) with unmet needs for specialist palliative care services.¹³⁴⁶ The committee heard that some communities have no palliative care specialist services.¹³⁴⁷

According to PCQ, Queensland's population of five million has access to only 100 palliative care specialists.¹³⁴⁸ Palliative Care Queensland explained further:

There is an urgent need to increase the number of specialist palliative care physicians. There are vast areas and regions of Queensland that do not have access to a specialist palliative care physician (for example, Mackay). There is also inequity across the regions. For example, the

¹³³⁹ Submission 1891, p 17.

¹³⁴⁰ Australian Institute of Health and Welfare, *Palliative care Services in Australia*, <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/overview>.

¹³⁴¹ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 24.

¹³⁴² Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 21.

¹³⁴³ Queensland Health, correspondence dated 6 December 2018, p 9.

¹³⁴⁴ Palliative Care Queensland, submission 1891, p 3.

¹³⁴⁵ See, for example, submissions 1202, 1233, 1261, 1268, 1280, 1282, 1285, 1288, 1891, 2604; Dr Anthony Herbert, Health Professionals Say No!, public hearing transcript, Brisbane, 23 August 2019, p 33; Ms Anne Curtis, Engagement Consultant, Health Consumers Queensland, Public hearing transcript, Brisbane, 13 September 2019, p 23.

¹³⁴⁶ Unpublished research by Palliative Care Outcomes Collaboration (PCOC), as quoted in Queensland University of Technology, *Palliative Care Services Review: Commissioned External Literature Review*, Deliverable 4: Final Report, January 2019, p 22.

¹³⁴⁷ See, for example, Dr Karen Murphy, Executive Director, Medical Services, North West Hospital and Health Service, public hearing transcript, Mount Isa, 31 May 2019, p 8; Mrs Michelle Williams, public hearing transcript, Ipswich, 9 September 2019, p 34.

¹³⁴⁸ Submission 1891, p 21.

*Darling Downs Hospital and Health Service (HHS) has a population of 280,000 people and has one palliative care physician; whereas Metro North HHS has a population of 900,000 and has eight palliative care physicians. It is important to note that the vast majority of these palliative care physicians are hospital based, and do not work in the community, leaving a significant gap in home based palliative care.*¹³⁴⁹

In regard to the impact on service delivery due to location, PCQ further stated:

Between 41% -76% of people with life limiting illnesses will require specialist palliative care services. A recent review undertaken by Queensland University of Technology found there are not enough specialist palliative care physicians to meet the needs of Queensland. There are 'blackspots' in care provision, particularly evident through the Western Central corridor where there is an ageing population and limited services (QUT report 2019). Services are inequitable because of geography. Specific examples include:

- *Townsville has a population of 250,000 and 3 specialist palliative care physicians whereas Mackay has a population of 125,000 and no specialist palliative care physician;*
- *Mt Isa has a visiting locum only.*¹³⁵⁰

The Australian Association of Social Workers raised similar issues regarding small numbers of palliative care specialists:

Specialist palliative care services are excellent. There are simply not enough, particularly in regional and remote areas. It is therefore not always possible to transfer to people to specialist Palliative Care Units and they remain in other hospital wards;

*When unable to access specialist palliative care, people are not always able to experience dying with dignity.*¹³⁵¹

The low numbers of specialists also impacts on their own health and wellbeing, as noted by PCQ :

*The limited number of palliative care physicians in some areas of Queensland potentially creates health and wellbeing issues for this group of health professionals. For example, in the Sunshine Coast HHS there is one specialist palliative care physician on 24 hour call every second or third night 365 days of the year, year in and year out. These specialist physicians are clinically responsible for the specialist level palliative care management for an increasingly high volume of clients in the acute and community sector.*¹³⁵²

The need to increase the palliative care workforce is discussed further at section 17.2.1 of this report.

15.2.4 Providing palliative care in hospitals

Queensland Health funds HHSs and non-government organisations (NGOs) to provide palliative care services in hospital environments. The department explained the current system for delivering palliative care services in Queensland:

Queensland's HHSs provide specialist palliative care services, including in-patient care in a designated bed, consultation liaison and outpatient services in the acute hospital setting and specialist palliative care advice and support to home and community-based care organisations and residential aged care facilities. Demand for these inpatient and outpatient services is high. Non-government community providers deliver care in different ways with some providing home and community-based care only, others providing hospice bed-based care only and others

¹³⁴⁹ Submission 1891, p 22.

¹³⁵⁰ Submission 1891, p 20.

¹³⁵¹ Submission 1288, p 12.

¹³⁵² Submission 1891, p 23.

*providing both. Palliative care can include a range of options depending on the patient's needs.*¹³⁵³

The Palliative Care Services Review reported that, in 2017-2018, there were 11,438 palliative care 'separations' across Queensland. Separations are defined as 'an episode of care for an admitted patient'.¹³⁵⁴ Approximately 100,000 days of specialist palliative care were provided in Queensland hospitals during the period, and 64 percent of these days were in public hospitals. The average length of stay for each episode of care was nine days.¹³⁵⁵ Stays can last much longer.¹³⁵⁶

15.2.4.1 Palliative care in hospitals - stakeholder concerns and suggestions

In regards to palliative care services delivered in hospital settings, inquiry stakeholders raised issues regarding the industry's workforce, resourcing and level of care provided to patients.

Funding issues and workforce are further outlined in chapters 16 and 17 respectively.

The level and types of services available varies from hospital to hospital, and this is reflected in the comments shared with the committee during the inquiry.

Other stakeholders raised concerns that hospitals did not have specific palliative care facilities or were not equipped to provide end of life care.¹³⁵⁷

Ms Mary Quilty who appeared before the committee in Mount Isa, outlined her mother's experience of palliative care at a local hospital:

*There was no palliative care facility at the hospital. We were put in a room that was a storage room. We were moved five times within five days to different rooms. There was no communication: 'Your mum is dying.' Like others have said, people do not say where you are up to. Even in terms of calling family to actually tell them to come in and be part of the last days, we were unsure whether or not it was her last days. Who is going to tell you that? I have found that every situation is very different. Nobody knows what is going on. It is hard to get answers for the family or especially for the partner of the person who is going through this.*¹³⁵⁸

Mr Ben Tennyson told the committee of the experiences of his mother, Pamela Tennyson, who had spent 100 days in a palliative care unit at a local hospital before being 'sent home, without her consent, to die'.¹³⁵⁹ Mr Tennyson outlined examples of substandard care delivered by nursing staff, and said he and his family members were not consulted appropriately in regards to his mother being discharged.¹³⁶⁰

Mr Tennyson recommended a number of changes to improve service delivery in hospital settings, including a clear policy about discharge of patients from palliative care facilities, providing patients and their families with clearer written information about palliative care, clear professional standards for

¹³⁵³ Queensland Health, *Queensland Health Palliative Care Service Review: Initial Outcomes*, p 2, https://www.health.qld.gov.au/__data/assets/pdf_file/0037/848359/palliative-care-services-review.pdf.

¹³⁵⁴ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 15.

¹³⁵⁵ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, pp 15-16.

¹³⁵⁶ Mr Ben Tennyson, public hearing transcript, Brisbane, 4 July 2019, p 89.

¹³⁵⁷ See, for example, submissions 1245, 1301, 1305, 1360, 1891, E070, E551; Ms Mary Quilty, public hearing transcript, Mount Isa, 31 May 2019, p 24.

¹³⁵⁸ Public hearing transcript, Mount Isa, 31 May 2019, p 24.

¹³⁵⁹ Public hearing transcript, Brisbane, 4 July 2019, p 89.

¹³⁶⁰ Public hearing transcript, Brisbane, 4 July 2019, p 89-90.

staff, and an ability for patients and family members to speak to appropriate personnel regarding any allegations of substandard care or harm by staff.¹³⁶¹

Ms Janine Lord told the committee her mother's final days in hospital were terrible to watch:

*...the focus of staff was on the living, not on the dying, and she was deprived of palliative care until her last few days.*¹³⁶²

Some individuals described a sense of being fearful for their loved ones being admitted to hospital.¹³⁶³

In contrast, Ms Valerie Cherrie told the committee:

*In 1989 I sat with my dad while he died in palliative care. He had the most, if I dare say so, beautiful death. He was peaceful; he was calm. It was absolutely wonderful and a privilege for me to be there with my dad when he died. He was one day off 90. It is still very vivid in my mind how peaceful and lovely he was.*¹³⁶⁴

Similarly, Mr Trevor Kucks advised:

*I have been directly involved in the end-of-life, palliative and hospice care for my own parents, my parents-in-law and just three years ago my own wife's passing from metastatic breast cancer. I nursed her at home for the last 12 months until she had to go to Ipswich Hospital palliative care initially and then to Ipswich Hospice Care. I cannot speak highly enough of the wonderful, compassionate, expert care that we received there.*¹³⁶⁵

Dr Philip Good acknowledged that 'Not everywhere is going to have a palliative care unit. There are a lot of hospitals throughout Queensland that have dedicated palliative care beds that are not palliative care units—for example, in rural areas'.¹³⁶⁶

Chapter 23 discusses the effectiveness of palliative care services in Queensland.

15.2.5 Providing palliative care in residential aged care facilities

Many patients receiving palliative care who become too ill to live in their own homes move to residential aged care facilities (RACFs) where they can access a range of care options and accommodation. Residential aged care in Australia is subsidised by the Commonwealth Government with the *Aged Care Act 1997 (Cth)* providing the legal framework.¹³⁶⁷

Queensland Health advised that each RACF resident usually has a nominated GP who can deliver or refer to palliative care services. Residents are eligible to receive a limited number of funded palliative care services in their facility through the Australian Government's Aged Care Funding Instrument, which allocates funding resources based on the needs of aged care residents.¹³⁶⁸

¹³⁶¹ Public hearing transcript, Brisbane, 4 July 2019, p 90-91.

¹³⁶² Submission E1222.

¹³⁶³ See, for example, submissions 258, 777, E484; Ms Mary Quilty, public hearing transcript, Mount Isa, 31 May 2019, p 24; Father Peter Tonti, public hearing transcript, Bundaberg, 16 July 2019, p 13.

¹³⁶⁴ Public hearing transcript, Ipswich, 9 September 2019, p 23.

¹³⁶⁵ Public hearing transcript, Ipswich, 9 September 2019, p 21.

¹³⁶⁶ Public hearing transcript, Brisbane, 5 April 2019, p 12.

¹³⁶⁷ Australian Government, Department of Health, *About residential care*, <https://agedcare.health.gov.au/programs-services/residential-care/about-residential-care>.

¹³⁶⁸ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 20.

In 2016-17, there were 43,971 permanent residents of RACFs in Queensland. Aged Care Funding Instrument appraisal figures indicate that approximately 1.8% (616) of those permanent residents required the provision of palliative care.¹³⁶⁹

15.2.5.1 *Palliative care in Residential Aged Care Facilities - stakeholder concerns and suggestions*

The committee heard of difficulties regarding the delivery of palliative care services in RACFs.

AMA Queensland suggested its members indicated ‘the medical care offered to patients who move into RACFs is fractured and difficult to access’,¹³⁷⁰ and in relation to palliative care called on the Queensland Government to ‘lobby the Commonwealth Government for increased Medicare payments for GPs and other allied health groups to provide palliative treatment to patients in RACFs. Increased medical treatment in RACFs is an efficient way of treating patients and will relieve pressure on acute treatment beds in hospitals’.¹³⁷¹

The AMAQ also recommended that ‘more attention be placed on the interface between palliative care and aged care’.¹³⁷²

The Australian Association of Social Workers also commented on the negative impact caused by the interface between RACFs and other health services. It stated:

*While health services have expertise in managing palliation, the interface between residential aged care and health is poor and lack of resources for community-based specialist palliative care is an ongoing issue. This impacts people’s access to care. For example, one Hospital and Health Service region in south-east Queensland has palliative care nurses to support residential aged care facilities, but no dedicated medical or allied health members. Regional and remote services are more reliant on GPs and visiting medical specialists for palliative support. This limits the ability of residential aged care facilities to access specialist palliative support from the health sector. Pain relief can also be an issue after hours and on weekends. If unable to access an after-hours doctor, people often have to be sent to hospital to access morphine to manage pain.*¹³⁷³

To improve delivery of palliative and end-of-life care, the AASW recommended an increase in residential aged care facilities with dedicated palliative care services, or access to community-based specialist palliative care.¹³⁷⁴

St Vincent’s Health Australia raised the need to increase capacity of specialist palliative care service support to RACFs and explained;

*There is a current gap for specialist palliative care services to provide medical and nursing support and education. There is large variation across Queensland as to what is provided from community specialist palliative care services to Residential Aged Care Facilities (RACFs). It can be challenging for RACF staff to deal with patients who are dying and support is needed. A program to up skill RACF staff and GPs as well as providing consult/share care with GPs is needed. SVHA believes that each RACF should have direct linkages to community specialist care services and that the palliative care providers do regular rounds at the facility.*¹³⁷⁵

¹³⁶⁹ Queensland University of Technology, *Palliative Care Services Review: Commissioned External Literature Review*, Deliverable 4: Final Report, January 2019, p 27.

¹³⁷⁰ Submission 1233, p 6.

¹³⁷¹ Submission 1233, p 6.

¹³⁷² Submission 1233, p 6.

¹³⁷³ Submission 1288, p 19.

¹³⁷⁴ Submission 1288, p 20.

¹³⁷⁵ Submission 1280, p 26.

15.2.6 Providing in-home and community-based palliative care

A key goal of palliative care is to provide support for clients in their preferred place of care. Many people choose to receive end of life and palliative care at home. Factors determining whether a person stays at home rather than moving to a hospital or RACF include:

- the level of care required for their illness or condition
- their home environment
- how much support they have from family or carers in their community
- whether someone is at home to care for them.¹³⁷⁶

The following services may be able to provide support for people choosing to remain at home:

- community and in-home nursing services
- Community Care program
- access to medical aids and equipment
- Hospital in the Home service (provides high-level care in the home)
- PalAssist – a Queensland-wide, free 24-hour telephone and online service for palliative care patients, carers, family and friends.¹³⁷⁷

According to the Grattan Institute, 70 percent of Australians state that they would like to die in their own homes; however, only 14 percent do.¹³⁷⁸ Hospitals and residential aged care facilities are their least preferred place to die.¹³⁷⁹ According to a study by the Grattan Institute, over the past 100 years home deaths have declined and hospital and residential care deaths have increased, and approximately 54 percent of people die in hospitals and 32 percent die in residential care.¹³⁸⁰

Palliative Care Queensland highlighted the importance of community networks in delivering quality palliative care.¹³⁸¹

To improve community networks to support palliative care, PCQ is undertaking a program called 'Queensland Compassionate Communities' which aims to connect and nurture networks around Queenslanders at the end of life through:

- *Building partnerships and enhancing existing partnerships with local community groups and key organisations*
- *Identifying existing community groups and key organisations and helping them to understand what they could do to support their community members at the end of life*
- *Developing resources / projects to help support existing community groups and key organisations to support their community members at the end of life*
- *Working with existing community groups and key organisations to establish and implement a Queensland Compassionate Communities charter/guidelines*

¹³⁷⁶ Queensland Government, 'Care at home', <https://www.qld.gov.au/health/support/end-of-life/care/care-at-home>.

¹³⁷⁷ Queensland Government, Care at home, <https://www.qld.gov.au/health/support/end-of-life/care/care-at-home>.

¹³⁷⁸ Submission 24, p 7.

¹³⁷⁹ Submission 24, p 7.

¹³⁸⁰ Submission 24, p 7.

¹³⁸¹ Submission 1891, p 31.

- *Being a central body to showcase & link compassionate communities in Queensland together.*¹³⁸²

Professor Patsy Yates told the committee about a current initiative to improve end-of-life care for older people in both residential and community care settings, which includes working with aged-care services and specialist palliative care services to build capability.¹³⁸³ The End of Life Directions for Aged Care (ELDAC) provides information, guidance, and resources to health professionals and aged care workers to support palliative care and advance care planning to improve the care of older Australians.¹³⁸⁴ It acts as a national specialist palliative care and advance care planning advisory service, and includes a suite of online resources and a telephone advisory service.¹³⁸⁵ The program is ‘building linkages between healthcare providers in specialist palliative care services and in the aged care sector with the aim of improving the quality of care for people in residential and community aged care settings’.

Professor Yates said the following about the program:

*That program, again funded through the Commonwealth, is about improving end-of-life care for older people in both residential and community care settings. We are now two years into that program. That program has four main streams of work. One is around embedding tools and resources to help aged-care providers, embedding some digital solutions to have access to information and, on the ground, we have employed what we call our partnership facilitators who are working with aged-care providers to see how you can build a link between an aged-care service and a specialist palliative care service to build capability. It is quite an innovative program.*¹³⁸⁶

15.2.6.1 In-home and community-based palliative care - stakeholder concerns and suggestions

Stakeholders highlighted the need to improve access to, and delivery of, services to allow a person to stay at home at end of life. The committee heard that more support is needed to improve these services.

Brisbane South Primary Health Network acknowledged the challenges for providing palliative care at home:

*Access to the appropriate services for aged and palliative care is a challenge for many. Palliative care services in the home are limited, meaning that many who would prefer to die in their own home are unable to do so.*¹³⁸⁷

Palliative Care Queensland also outlined the barriers to people accessing palliative care at every service level.¹³⁸⁸ Palliative Care Queensland stated ‘the lack of resources in the community limits family capacity to provide end of life care for a loved one at home’,¹³⁸⁹ and outlined research that suggested:

¹³⁸² Palliative Care Queensland, *Queensland Compassionate Communities is the community arm of Palliative Care Queensland*, <https://palliativecareqld.org.au/qcc/>.

¹³⁸³ Public hearing transcript, Brisbane, 5 July 2019, p 39.

¹³⁸⁴ End of Life Directions for Aged Care, <https://www.eldac.com.au/>.

¹³⁸⁵ End of Life Directions for Aged Care, *About the Project*, <https://www.eldac.com.au/tabid/4895/Default.aspx>.

¹³⁸⁶ Professor Patsy Yates, Deputy Vice-Chancellor and Vice-President (Research and Innovation), Queensland University of Technology, public hearing transcript, Brisbane, 5 July 2019, p 39.

¹³⁸⁷ Ms Lucille Chalmers, General Manager Commissioned Programs, Brisbane South Primary Health Network, Public hearing transcript, Brisbane, 4 July 2019, p 45.

¹³⁸⁸ Submission 1891, p 23.

¹³⁸⁹ Submission 1891, p 23.

- *Additional services, such as a discharge nurse are necessary to enhance rapid discharge in the last days of life.*
- *Transition home from hospital in last days of life is resource intensive and unsustainable within current structures.*
- *Families carry direct and indirect costs for end of life care including transportation to services, medications, continence products, laundry, as well as emotional and spiritual burden with little support.*¹³⁹⁰

Palliative Care Queensland recommended the exploration of community-based palliative care models (including hospice models) to assist families to keep their loved ones at home near end of life.¹³⁹¹

The Royal Australasian College of Physicians supported the need to improve the delivery of palliative care services in home and community settings:

*It is crucial that adequate resources are allocated at a state level towards supporting patients wishing to die at home, in a hospice or in a residential aged care facility. The RACP calls on the Queensland government to work with Australian Government on the development of flexible, population-based, integrated models of care that improve the provision of palliative care services in non-hospital settings.*¹³⁹²

St Vincent's Health Australia outlined in their submission, a pilot program conducted in partnership with Bupa, to provide palliative care services for Bupa members in their homes in the community. St Vincent's Health Australia submitted:

This program aimed to increase access to palliative care services for Bupa patients and their carers and provide them with greater support in the community. The results demonstrated:

- *Increased home death rates*
- *Decreased acute hospital death rates*
- *Very high preferred place of death achieved*
- *Very high patient/carers satisfaction*
- *Substantial cost saving per patient.*

*One of the more important findings from this study was that a preference for a home death depended on service availability and expectations of patient and family. It showed that if there is more support in the community available to patients and carers then more people want to die at home, and more people actually do die at home.*¹³⁹³

Palliative Care Queensland stated that home-based hospice services may reduce barriers to discharging clients from hospital including health professionals' fear of litigation related to perceived accountability for managing potential risks.¹³⁹⁴ Palliative Care Queensland explained that its experience in one southeast Queensland jurisdiction was that there was widespread concern from health professionals about the process of discharging clients home to die, and noted that these concerns were derived from limited access to resources.¹³⁹⁵

¹³⁹⁰ Submission 1891, p 23.

¹³⁹¹ Submission 1891, p 23.

¹³⁹² Submission 1203, p 3.

¹³⁹³ Submission 1280, p 22.

¹³⁹⁴ Submission 1891, p 23.

¹³⁹⁵ Submission 1891, p 24.

Miss Karen MacKellar, a palliative care clinical nurse consultant, contrasted the level of assistance for home-based palliative care in Queensland to that of England and stated:

I come from a background where in England, if somebody wanted to go home and die, within 24 hours I could have four nursing visits a day. We had hospice in the home 24 hours a day for people in their last days of life. I came here to find that, unless people already had a package of care in place—so had already been approved for a level 4 package—or they were imminently dying, in their last three months of life, where our program could provide the funding for a maximum of an hour a day, there was nothing there.

...

*We cannot do palliative care in the home without more resources there to support these patients. It is impossible. Until we have rapid access to comprehensive packages of care for these patients, we are never going to achieve patients' wishes to die at home.*¹³⁹⁶

Improving palliative care in the home - Home Care packages

Some stakeholders suggested delivery of palliative care services could be improved through the introduction of a stand-alone palliative home care package system.¹³⁹⁷

While it was noted some home-care packages provided by the Australian Government to support aged care can be utilised for some services related to end-of-life care, there is no specific provision for end-of-life or palliative care.

The Uniting Church in Australia Queensland Synod explained the current position:

*Current community-based aged care and disability funding does not generally cover palliative care as it is designed to improve capability and wellbeing for people to remain in community. People with terminal conditions do benefit from this approach, but need more support as their disease progresses.*¹³⁹⁸

Dr Louise Welch, of the Queensland Specialist Palliative Care Services Medical Director's Group also noted that existing aged care packages do not include 'hands-on nursing',¹³⁹⁹ which would be necessary for a person who is palliative.

The Grattan Institute recommended introduction of specific community-based palliative care packages to support people who want to die at home.¹⁴⁰⁰

The submission from PCQ similarly recommended palliative care packages as follows:

*An idea that needs full consideration is establishment of palliative care home care packages (PCHCP) – with the allocation of approved funds being made in accordance with the client's needs and in accordance with medically determined life prognosis predictions. PCHCP funding can be directed to a provider of the client's choice, and it will be the provider's responsibility to ensure sufficient funds are available to meet the need for increased nursing support, equipment and potential after hours support as the person approaches the terminal phase of care.*¹⁴⁰¹

Dr Andrew Broadbent, of the Queensland Specialist Palliative Care Services Medical Directors' Group (QSPCSMDG) outlined the use of an 'end-of-life package' available in New South Wales called ComPacks, and another available through a consortium of HammondCare, St Vincent's and Calvary in

¹³⁹⁶ Public hearing transcript, Toowoomba, 17 May 2019, p 30.

¹³⁹⁷ See, for example, submissions 24, 1229, 1891.

¹³⁹⁸ Submission 1268, p 26.

¹³⁹⁹ Public hearing transcript, Brisbane, 5 April 2019, p 4.

¹⁴⁰⁰ Submission 24, p27.

¹⁴⁰¹ Submission 1891, p 53.

Sydney. Mr Broadbent stated that the ComPack packages make ‘...a huge difference’¹⁴⁰² and can allow a person to receive assistance from a carer or nurse which can be particularly beneficial to a person at night.¹⁴⁰³

The Anglican Church of Southern Queensland recommended improved funding and resources, including home care packages to include funding for pastoral and spiritual care.¹⁴⁰⁴

Access to equipment

According to stakeholders, one of the main barriers to keeping family members who are palliative at home is inadequate access to equipment. Examples given included the need for hospital beds (or similar), shower chairs and mobility equipment.¹⁴⁰⁵

Ms Kate Gallaway, Chief Executive Officer, NPA Family and Community Services Aboriginal and Torres Strait Islander Corporation, explained:

*... because this is being provided in home, what we need is equipment like a hospital bed so that if someone wants to pass away at home we can loan them the bed that they can use at home because normal beds are not always appropriate for delivering end-of-life care. ... It is not like we need a large amount of equipment. It is equipment that can be loaned out to families during that end-of-life process.*¹⁴⁰⁶

The Australian Association of Social Workers noted the financial burden of having to buy or loan equipment:

*When people are receiving higher level care packages they must use their package funds to access equipment. This can be costly, and renting or buying second hand may not be an option for some individuals or their families. Therefore, the person must decide whether to purchase equipment they need to remain in their home and relinquish certain care requirements, or face entry into residential aged care.*¹⁴⁰⁷

Access to GPs and other health professionals

Stakeholders also noted the unavailability of GPs and other health professionals to assist with palliative care, particularly outside of normal business hours.

Ms Anne Joyce, a nurse practitioner with almost 18 years’ work in the palliative care sector told the committee ‘...in our region, there is a limited number of GPs who will do home visits. It is not fair to expect these few to take on the care of other GPs patients. These patients will need regular visits, out of hours phone support, family support and after death paperwork’.

She provided the following example of what will happen:

A community palliative care client may have an unexpected escalation of pain in the evening or on the weekend. They cannot access their GP out of hours, Dial a Doctor can’t come for several hours and may only provide short term pain relief, the community nursing team cannot adjust medications – the only option is to call QAS to go to Emergency. They may be admitted to get the pain under control, their condition deteriorates while in hospital, they die in an acute care

¹⁴⁰² Public hearing transcript, Brisbane, 5 April 2019, p 5.

¹⁴⁰³ Public hearing transcript, Brisbane, 5 April 2019, p 5.

¹⁴⁰⁴ Submission 1229, p 11.

¹⁴⁰⁵ See, for example, Ms Kate Gallaway, Chief Executive Officer, NPA Family and Community Services Aboriginal and Torres Strait Islander Corporation, public hearing transcript, Cairns, 28 May 2019, p 7; submissions E912, E1100, 1234, 1243.

¹⁴⁰⁶ Ms Kate Gallaway, Chief Executive Officer, NPA Family and Community Services Aboriginal and Torres Strait Islander Corporation, public hearing transcript, Cairns, 28 May 2019, p 7.

¹⁴⁰⁷ Submission 1288, p 19.

*bed and not at home which was their wish – and could have been achieved with adequate support.*¹⁴⁰⁸

A nurse with over 36 years' experience in Queensland also reflected on her own experiences with rural patients who had returned home, stating that 'their challenges are very real'. Decima Jones reflected on a case where one of her patients wanted to be at home (five hours west of Brisbane); however, there was no local service that could provide nurses over a weekend to change a syringe driver for pain control:

*The patient chose initially to put up with more pain to stay at home but was eventually admitted to the local hospital for his End of Life care because he could no longer swallow his medication and needed a syringe driver for pain control.*¹⁴⁰⁹

15.2.7 Providing palliative care in hospices

As explained in section 14.2.3, Queensland has a small number of hospices run by non-government organisations with some providing inpatient and home care and others providing home care only.¹⁴¹⁰

The Acting Director of Nursing at Ipswich Hospice Care Inc. provided insight into the hospice model of care:

The ability to provide hospice type care is severely limited in Queensland due to the scarcity of services, and it is our recommendation that any development of palliative care services across the state should include both inpatient and community based hospice care.

*The value of the hospice model is sometimes difficult to articulate as, by nature, it consists of a number of elements that need to exist together in order to bring about the benefits experienced. These include responding to the needs and desires of individuals and their families and understanding that the physical care provided needs to be matched with spiritual and psychological care and flexibility. Care in hospices acts as a bridge between the home and the hospital, providing patients and their families 24/7 clinical care but in a more home-like environment than a hospital provides.*¹⁴¹¹

Mr Mark Hunter, who appeared before the committee at its public hearing in Southport, advocated for a hospice model being a viable choice, and stated:

*In advocating for hospice, it is a difficult situation because we only have three hospices in Queensland—we have outreach services as well—whereas if we compare that situation with New Zealand where they have 31 hospices then it becomes a viable choice. In actual fact, in New Zealand a significant percentage of people who die as a result of age die in a hospice. Hospices are homelike. They have specialist consistent nurses and nursing and a dedicated skilled volunteer workforce. It is a whole-person approach. It is highly responsive and a flexible environment.*¹⁴¹²

The Anglican Church of Southern Queensland also supported the provision of further funding and resources to increase the availability and use of hospice models of care.¹⁴¹³

¹⁴⁰⁸ Submission 2316, p 2.

¹⁴⁰⁹ Submission 1360, p 5.

¹⁴¹⁰ Queensland Health, *Queensland Health Palliative Care Service Review: Initial Outcomes*, p 2, https://www.health.qld.gov.au/__data/assets/pdf_file/0037/848359/palliative-care-services-review.pdf.

¹⁴¹¹ Ms Rosie Laidlaw, Acting Director of Nursing, Ipswich Hospice Care Inc., public hearing transcript, Ipswich, 9 September 2019, p 4.

¹⁴¹² Public hearing transcript, Southport, 10 September 2019, p 43.

¹⁴¹³ Submission 1229, p 12.

Dr Richard Osborne, Consultant in Medical Oncology, Clinical Director, Cancer Care Service, Wide Bay Hospital and Health Service, advised the committee that the Wide Bay Hospital and Health Service had recently been granted funds from the state government to establish a hospice in Hervey Bay.

This involves money for building the hospice and running it for three years. Figures quoted by Dr Osborne were \$3 million for building the hospice and \$1.5 million to run it for the next three years. Dr Osborne said that the prospect is for the new facility to be established and up and running within the next year and that the hospice will serve Hervey Bay and Maryborough. Dr Osborne said that it is going to be six to eight beds to start off with and then probably opening another four to six after that.¹⁴¹⁴

15.2.8 Providing after-hours palliative care services

A significant issue raised by stakeholders was inadequate access to health professionals after-hours. This was raised in regards to accessibility of services for persons at home, as well as those residing in health facilities.

Stakeholders stressed that a person's suffering does not cease after business hours or on the weekend.

Ms Moira Crowson, told the committee:

*Babies are born at all times of the day and night, every day of the week and so, too, people die every minute of every day. A home hospice service that operates office hours, Monday to Friday, is simply not good enough. Not being able to contact a doctor to sign a death certificate at one o'clock on a Saturday afternoon, after the NIKI pump had been inserted by the palliative care service the evening before, is scandalous.*¹⁴¹⁵

Many inquiry stakeholders commented on the lack of after-hours services in regional areas. When asked if Bundaberg residents get access to community palliative care on a weekend, Ms Debbie Carroll, Executive Director, Acute Hospital and Community Services at the Wide Bay Hospital and Health Service, said:

*There are issues. We script out for the care component, which might go to an external provider. At times there are problems with accessing that care. We try to set up the packages for the delivery of care over seven days, but I certainly know of some issues where people have struggled with accessing those services, particularly if you have to commence a syringe pump on the weekend. We only do Monday to Friday services.*¹⁴¹⁶

Miss Karen MacKellar who works as the Palliative Care Clinical Nurse Consultant at the Darling Downs Hospital and Health Service acknowledged the lack of after-hours palliative care programs outside Toowoomba:

In our service within Darling Downs we do have a community palliative care program where for people in the last three months of life we can fund nursing, for nurses to go in for up to an hour a day, so people who have syringe drivers can get syringe drivers done at home to enable them to stay at home. As I say, it is an hour a day and it is not equal across the health service. If you go out to our rural facilities such as Warwick, Goondiwindi or out west, there is no community nursing at weekends. If somebody has a syringe driver, we have families taking syringe drivers out to take them to the hospital to get refilled and take them back and put them back on the patients because there is no service at the weekend. I consider us lucky in Toowoomba. We have seven-day community nursing, but as soon as you go outside the Toowoomba area that does not

¹⁴¹⁴ Public hearing transcript, Hervey Bay, 15 July 2019, p 3.

¹⁴¹⁵ Public hearing transcript, Toowoomba, 17 May 2019, p 20.

¹⁴¹⁶ Public hearing transcript, Bundaberg, 16 July 2019, p 3.

*happen. Even within one health district, there is huge disparity about the services that can be provided.*¹⁴¹⁷

Similarly, at the public hearing in Gladstone, Ms Nicole Dickhaut, a practice manager at a general practice on Boyne Island, told the committee:

*When it comes to the CQHHS in Gladstone, it is correct that there are 1.4 FTE palliative care nurses, so there are two dedicated people. They work Monday to Friday, but when it comes to the weekend there is a problem. They do have a phone, but often if they cannot see that there is an end of life nearing in that weekend and they are not prepared by having the right scripts and the right medication, they are ringing everyone trying to find a GP.*¹⁴¹⁸

At the Rockhampton public hearing, Mr Steve Williamson the Health Service Chief Executive at the Central Queensland Hospital and Health Service told the committee that Rockhampton residents had access to a 7 day per week outreach service.¹⁴¹⁹ In answer to a question on notice in relation to that service Mr Williamson provided the following information:

*The Cancer Outreach Service (an outreach service of CIPU [Cancer Inpatient Unit]) is provided 7 days (hours of operation are 0700 -1530). There is no on-call. However, support is provided via phone and in-house visits. Patients are under the medical governance of a Palliative Care Specialist.*¹⁴²⁰

In relation to the availability of after-hours palliative care services in aged care facilities, Dr Lilantha Basnayake who works at the Toowoomba Hospital noted that in her experience, residential aged-care facilities did not have palliative care services available after hours.¹⁴²¹

Ms Bev and Mr Col Griffiths shared the story of the death of Bev's mother who had been living in a nursing home:

When my mother was dying, she was taken to the "Palliative Care Unit". This turned out to be virtually a room, tucked away from the main area, dedicated to be "Palliative Care".

The Nurse in Charge had telephone access to a Palliative Care Professional for pain management etc and I understood that a Palliative Care Nurse visited for consultation.

*This arrangement was far from satisfactory and my mother was unsettled, distressed and her pain was not managed. It was only intervention from a family member with a nursing background that we were able to get action and the pain relief that my mother needed. The Nurse in Charge with Palliative Care training was not available on weekends or evenings.*¹⁴²²

Palliative Care Queensland recommended RACFs should be able to access after-hours palliative care nurse practitioners, to support the facility in managing end-of-life care for residents with more complex needs. This in turn would help to reduce hospital presentations and admissions for these residents.¹⁴²³ In its submission to the inquiry PCQ explained:

A key concern is the quality and availability of after-hours care including weekend care for residents. Residents and their families need assurance that appropriate care will be provided in any 24 hour period including on weekends. This needs to include the staffing sufficient to ensure

¹⁴¹⁷ Public hearing transcript, Toowoomba, 17 May 2019, p 31.

¹⁴¹⁸ Public hearing transcript, Gladstone, 30 October 2019, p 24.

¹⁴¹⁹ Public hearing transcript, Rockhampton, 17 July 2019, p 7.

¹⁴²⁰ Central Queensland Hospital and Health Service, correspondence, dated 24 July 2019, attachment, p 3.

¹⁴²¹ Public hearing transcript, Toowoomba, 17 May 2019, p 2.

¹⁴²² Submission 1984, p 4.

¹⁴²³ Submission 1891, p 53.

*residents are able to receive palliative pain medication and symptom management at any time of the day or night.*¹⁴²⁴

The committee heard many calls for 24-hour access to palliative care.

Mr Tony Bull described his experience with the provision of services in the Wide Bay region, and called for extension of palliative care unit operating hours 'to include after hours, public holidays and weekends'.¹⁴²⁵ Mr Bull told the committee:

*... my wife's suffering during that weekend could have been avoided had a palliative care unit been operating and available, or a medical practitioner for advice and/or medical ministrations on a weekend. I am sure it is obvious to all that medical needs, including palliative, do not subside just because it is not a weekday.*¹⁴²⁶

Queensland Primary Health Networks recommended that on-call nursing services be available 'in the event of an acute episode after hours'.¹⁴²⁷

In her submission to the committee, nurse practitioner Ms Faye Tomlin commented that a lack of funding and resources led to a lack of 24/7 palliative care in regional communities:

As a nurse practitioner I am an experienced clinician in the delivery of end of life care within a regional area of Queensland. Currently, consumers and their families are referred to palliative care services but are often not supported until close to dying. Due to the lack of dedicated funding and resources may regional Queenslanders are referred back into hospital not by choice but due to the lack of 24/7 care available.

*It remains important to remember that we can never repeat what happens at the end of life. How a person lives and dies remains in the minds of many after they are gone. Palliative care should be seen as a basic human right for those in the last 12 months of life not an optional extra in the delivery of health care within Queensland.*¹⁴²⁸

The Cancer Council Queensland advised that it operates PalAssist, 'a 24-hour accessible online and telephone service that is free for anyone who has a life limiting illness or condition, and/or their families and carers'.¹⁴²⁹ The service is funded by Queensland Health, however, this service does not provide direct care in the case of an acute episode.

In its submission to the committee, St Vincent's Health Australia, called for an increase in resources for palliative care in Queensland.¹⁴³⁰ It submitted:

...people requiring palliative care services should have:

- *Access to direct admission to inpatient palliative care facilities 24/7;*
- *Access to specialist palliative care service advice (either in person or via videoconference facilities) 24/7; and*
- *Access to specialist community and home-based care.*¹⁴³¹

¹⁴²⁴ Submission 1891, p 46.

¹⁴²⁵ Public hearing transcript, Bundaberg, 16 July 2019, p 11.

¹⁴²⁶ Public hearing transcript, Bundaberg, 16 July 2019, p 11.

¹⁴²⁷ Submission 1301, p 10.

¹⁴²⁸ Submission 287, p 2.

¹⁴²⁹ Submission 1303, p 1.

¹⁴³⁰ Submission 1280, p 17.

¹⁴³¹ Submission 1280, p 22.

15.3 Equity of access to palliative care services

One of the key issues raised during the inquiry was the ability of all Queenslanders, regardless of their location, age, or cultural and linguistic background, to access the same level of quality palliative care.

Dr Parker, a palliative medicine specialist based in Brisbane, stated that ‘equitable access to comprehensive palliative care must be recognised as a fundamental human right and an essential component of value based, safe and high-quality health care for all’.¹⁴³² Dr Parker continued that palliative care ‘cannot and should not be considered an optional extra of health services any longer’:

*The people who experience a life-limiting illness potentially are and do become the most vulnerable members of our society. ... As experienced palliative medicine specialists, who together with our nursing, allied health and primary care colleagues are at the coalface of healthcare delivery, we are acutely aware of the gaps and inequity that exist across Queensland in the context of inadequate and disparate resourcing for the provision of a comprehensive palliative care system. To achieve the care that is individualised and concordant with the wishes and values of the person with a life-limiting illness requires planning, it requires delivery of care that is structured, flexible and considered and it requires the availability of responsive services 24 hours a day, seven days a week, irrespective of the setting. We do not have this down right.*¹⁴³³

Inequitable access to palliative care services across the state was raised as a significant issue, particularly for people in regional, rural and remote areas.¹⁴³⁴

The type and level of support required for patients receiving palliative care will vary depending on their needs. Support may range from dealing with more ‘straightforward medical problems’ to the need for specialist palliative care.¹⁴³⁵ In terms of delivering palliative care to patients requiring those different levels of support, academics from the Faculty of Medicine at the University of Queensland advised ‘[t]here are shortcomings in access to appropriate care for both groups of dying people’.¹⁴³⁶ They further advised:

It is unfortunate that in Australia it is estimated that only 40% of the 100,000 predictable deaths per annum that need specialist palliative care receive it. For those receiving specialist palliative care, 80% do not have severe symptoms at the time of death. Unfortunately not all dying people are able to access palliative care service.

...

*Supportive care whereby people are supported throughout old age (eg in terms of mobility, disease and symptom management, and dementia) is vital and, in many cases, can support people through the end-of-life phase. Indeed it is not possible for specialist palliative care to be involved in every death. Education and end-of-life care, and a willingness by treating physicians to introduce supportive care early, needs to be a routine part of all care in all settings, and this will require extensive education and support to achieve.*¹⁴³⁷

¹⁴³² Dr Greg Parker, public hearing transcript, Brisbane, 5 April 2019, p 3.

¹⁴³³ Dr Greg Parker, public hearing transcript, Brisbane, 5 April 2019, p 2.

¹⁴³⁴ QNMU, submission 1213, p 28; COTA Queensland, submission 1304, p 24; Dr G Parker, public hearing transcript, Brisbane, 5 April 2019, p 3; Cancer Council Queensland submission 1303, p 8; National Seniors Australia submission 1309, p 10.

¹⁴³⁵ Faculty of Medicine, University of Queensland, submission 1219, pp 5-6. NB: in-text references have been removed. Refer to original source for more information.

¹⁴³⁶ Faculty of Medicine, University of Queensland, submission 1219, pp 5-6. NB: in-text references have been removed. Refer to original source for more information.

¹⁴³⁷ Faculty of Medicine, University of Queensland, submission 1219, p 6. NB: in-text references have been removed. Refer to original source for more information.

The QNMU stated that palliative care services ‘are of undoubtedly high quality’ but that ‘due to a range of structural, organisational, service provision and funding issues it is likely a significant number of Queenslanders do not receive palliative care that fully reflects their needs or choices’.¹⁴³⁸

15.3.1 Access to palliative care services in regional, rural and remote communities

Queensland is the second largest state in Australia with an area of 1,727,000 square kilometres.¹⁴³⁹ While much of the population is concentrated along the coast, patients require the same palliative care in regional, remote and rural areas of the state.

One of the key issues raised during the inquiry was the ability of all Queenslanders, regardless of their location, age, or cultural and linguistic background, to access quality palliative and end-of-life care.

The RANZCP stressed the importance of equitable and quality palliative care, regardless of location:

*All Queenslanders should have timely and equitable access to properly resourced, high quality, palliative care and end-of-life care, whether in a hospice, hospital or home based setting. Equitable access to care is particularly important for people residing in rural and regional locations.*¹⁴⁴⁰

The committee heard from a number of submitters and witnesses about the difficulties of accessing palliative care services outside South East Queensland.

Ms Veronica Box spoke of her experiences accessing services in the Mary-Burnett region:

*In regional and remote areas it is very difficult to arrange palliative care. In many or most areas away from the major cities there is no direct access to specialist palliative care. When it is available there is serious understaffing. There are not enough resources and no beds available when required.*¹⁴⁴¹

Ms Box submitted:

*I heard many stories of loved ones being unable to access palliative care. Often they had to remain in a nursing home or be admitted to a public ward if there was a bed available. I have been told that staff in nursing homes were not qualified to attend to their needs and families felt unwelcome when they tried to help or intervene. If a bed could be found it was often far from home so that the ageing spouse often had to find accommodation, which could be quite expensive. State and federal governments must show, by more funding for resources, that Australians in the bush are just as entitled to good palliative care as those in the cities.*¹⁴⁴²

Southern Cross Care also attested to a shortage of palliative care services:

*... there is insufficient access to specialist palliative care services, particularly in rural and regional communities. Equitable access to palliative care services should be considered a priority because it improves the quality of life of care recipients and their families facing life-threatening illness.*¹⁴⁴³

According to Catholic Health Australia, workforce shortages are a significant barrier to equitable access to services:

¹⁴³⁸ Submission 1213, p 27.

¹⁴³⁹ Queensland Government, *Interesting facts about Queensland*, <https://www.qld.gov.au/about/about-queensland/statistics-facts/facts>.

¹⁴⁴⁰ Submission 1207, p 8.

¹⁴⁴¹ Public hearing transcript, Caloundra, 3 May 2019, p 19.

¹⁴⁴² Public hearing transcript, Caloundra, 3 May 2019, p 20.

¹⁴⁴³ Submission 1245, p 4.

*In our experience in regional areas, patients of tertiary services are also significantly less likely to receive specialist PC services, likely as a result of the necessity of PC to be delivered in other areas of the hospital due to limited specialist staff and dedicated facilities. While this does not necessarily mean that the quality of care is poor, however, it is reasonable to assume that specialist PC physicians are able to provide better PC than non-specialists.*¹⁴⁴⁴

CentrecareCQ referred to a lack of services in certain locations, and the impact of having to move people from their local area to access facilities that are appropriately resourced, as challenges for delivering palliative and end-of-life care in regional, rural and remote Queensland:

*Availability of resources such as medical staff with skills and experience. Availability of beds in small locations. There are current examples of people being sent well out of their local area to access hospital or residential facilities that are appropriately resourced. There is not a well-coordinated mobile workforce that can support the smaller medical and community resources to ensure that staying in rural areas is one of the options. We could look at models such as the SES, where people sign up to be activated for “away” work when needed. These folk have skills maintained and are deployed according to need. Managing risk for lone workers is another challenge.*¹⁴⁴⁵

The Grattan Institute submitted that:

*More work must be done on a regional and service governance model that gives people a better end to life.*¹⁴⁴⁶

Similarly, Dr Greg Parker told the committee:

*I think universal access and delivery of best possible palliative care, independent of prejudices, the postcodes we live in, the time of day or where the person may be in their terminal disease trajectory, requires a concerted effort from government, the healthcare system and the community to really improve the current landscape. We cannot leave this to chance any longer.*¹⁴⁴⁷

Dr Patricia Lee-Apostle, a palliative medicine specialist at the Toowoomba Hospital expressed a similar view:

*... a specific palliative care package needs to be equitable. There needs to be a statewide plan and not just a patch-up—‘Let’s do this for this place but not this place.’ There is a discrepancy with postcodes.*¹⁴⁴⁸

Ms Teeshan Johnson, the Executive Director of Cherish Life Queensland also commented ‘Place is important because we know that access to palliative care in Queensland is largely determined by postcode’.¹⁴⁴⁹

15.3.1.1 Inequitable distribution of resources

A key concern raised by stakeholders was the inequity of palliative care resourcing and provision across the state.¹⁴⁵⁰ According to the QNMU, inequitable distribution of funding was a significant reason for

¹⁴⁴⁴ Submission 1249, pp 7-8.

¹⁴⁴⁵ Submission 1297, p 9.

¹⁴⁴⁶ Submission 24, p 18.

¹⁴⁴⁷ Public hearing transcript, Brisbane, 5 April 2019, p 3.

¹⁴⁴⁸ Public hearing transcript, Toowoomba, 17 May 2019, p 7.

¹⁴⁴⁹ Public hearing transcript, Brisbane, 23 August 2019, p 25.

¹⁴⁵⁰ QNMU, submission 1213, p 28; COTA Queensland, submission 1304, p 24; Dr G Parker, public hearing transcript, Brisbane, 5 April 2019, p 3; Cancer Council Queensland submission 1303 page 8; National Seniors Australia submission 1309 page 10.

differences in delivering services across remote, rural, regional and metropolitan areas.¹⁴⁵¹ Palliative Care Queensland supported the view that funding did ‘not seem equitable throughout the regional, remote and rural areas compared to the metropolitan services’.¹⁴⁵² The PCQ submission elaborated further:

*... the provision of funding to subacute services, without specific activity outcomes related to community-based investment, **reduces** incentive for funding to flow to remote and rural areas. The funding does not always filter down to on the ground community based palliative care services. Instead funding goes into subacute services, such as rehabilitation. This disadvantages people with life limiting illnesses who are not able to receive services because of such funding decisions.*¹⁴⁵³ [Emphasis in original]

Palliative Care Nurses Australia agreed that, where available, specialist palliative care teams provided quality care but there were gaps in delivery of this care between metropolitan and regional and remote communities:

In areas served by specialist palliative care teams, such as Metropolitan Brisbane, Gold Coast, Sunshine Coast, and Townsville, a high standard of end of life care is able to be provided to people who need it. In those areas, excellent holistic care can be offered to patients at end of life and their families, regardless of whether they have complex needs or not. Holistic care includes symptom management, psychosocial care of patients and families, and bereavement care after death for the carers and families.

*However, there are regional and remote communities with no access to specialist palliative care services. Clinicians in these communities are required to contact specialist palliative care teams to seek advice. This places a burden on the already stretched specialist teams who are called upon to provide advice with limited knowledge of the person. For patients in these communities, holistic care is often difficult to achieve including the option of choice for place of care. Equitable access to palliative care is a human right and a fundamental component of safe, values based and high-quality health care.*¹⁴⁵⁴

Ms Susan Carr, who worked as a community nurse and aged care nurse, told the committee:

*We have current statistics that state that those in rural and remote areas have poorer health outcomes, we know that they are disadvantaged by lack of access to health services in general. We also know that many rural and remote elderly are left without family to support them due to being unable to sell their properties or businesses or even afford to live in metropolitan areas. There are very few to no choices at all for those in rural/remote areas to find any aged care facilities, effective palliative care services and least of all end of life options.*¹⁴⁵⁵

Queensland Health acknowledged that support services, such as general practitioner and allied health, varied across the state and that travel distances and workforce availability were issues for patients seeking palliative care services in regional and remote areas. The department stated:

...effective delivery of healthcare in rural and remote communities requires supportive policy, established Australian Government and State relations, and community readiness to be in place. It also acknowledged the benefits telehealth can provide to these communities through improved access to healthcare services and expertise.

¹⁴⁵¹ Submission 1213, p 28.

¹⁴⁵² Submission 1891, p 54.

¹⁴⁵³ Submission 1891, p 16.

¹⁴⁵⁴ Submission 1305, p 2.

¹⁴⁵⁵ Submission E265.

*The challenges to the delivery of health services and building and maintaining sustainability within the workforce in rural and remote areas are also highlighted in the Department's strategy, Advancing rural and remote service delivery through workforce: A strategy for Queensland 2017-2020. Small populations with diverse health needs, dispersion of communities and services and a small health workforce adds complexities that must be considered when managing the workforce. The Strategy outlines an integrated planning approach to implementing initiatives that are aligned with other key strategic documents to achieve its objective of, "positioning the rural and remote health workforce to deliver contemporary, appropriate and safe health services for rural and remote communities".*¹⁴⁵⁶

15.3.1.2 Travel and transportation of patients and practitioners

Cancer Council Queensland expressed concern about how limited access to services for people in regional, rural and remote Queensland may lead to patients having to be transported to and from their home towns to major hospitals and facilities.¹⁴⁵⁷

National Seniors Australia was also concerned about the 'tyranny of distance' which 'makes it difficult for carers, family and friends to support people receiving these services [palliative care] in hospital settings'.¹⁴⁵⁸

In terms of costs for clinicians, Health Consumers Queensland, PCQ, Council on the Ageing (COTA) Queensland, and Carers Qld Australia recommended in their joint submission that there be: 'Wider access to travel subsidies for rural and remote communities'.¹⁴⁵⁹

15.3.1.3 Availability of infrastructure and equipment

A number of submitters outlined for the committee how the lack of appropriate infrastructure and equipment affects the quality of palliative care provided in rural and remote areas.¹⁴⁶⁰

Dr Lee-Apostle advised the committee of some of the potential requirements of palliative services:

*When a lot of people deteriorate and are in the active stage of dying, they need specific equipment to help the carers as well as help them with things like—and this is not inclusive—beds, commodes or hoists if they need them. As I have said, it is dependent on the patient's situation—their habitus, how frail they are, how much they could move or if they are bed bound. Their needs are also dependent on if they have an open wound that needs to be dressed every day. Do they have special needs? Do they have a suprapubic catheter or an indwelling catheter that needs to be drained? Those all need to be considered.*¹⁴⁶¹

For Ms Shyla Mills, the Chief Executive Officer of PCQ, one of the biggest challenges facing remote areas was access to equipment:

The last thing to mention is equipment in regional areas. That is probably one of the biggest challenges—beds and manual handling. All of those sorts of things are really challenging. We talked a bit before about the Torres Strait. How do you get a bed to an island where they need one to keep them at home? I know one island told me that the community fundraised for their own fold-up bed so that it can be used to go into different houses so that it does not have to

¹⁴⁵⁶ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 36.

¹⁴⁵⁷ Submission 1303, p 8.

¹⁴⁵⁸ Submission 1309, p 10.

¹⁴⁵⁹ Joint submission from Health Consumers Queensland, PCQ, COTA Queensland, and Carers Qld Australia, submission 1892, p 11.

¹⁴⁶⁰ See for example ANZSPM, submission 1252, p 7.

¹⁴⁶¹ Dr Patricia Lee-Apostle, Palliative Medicine Specialist, Toowoomba Hospital, public hearing transcript, Toowoomba, 17 May 2019, p 6

*come on a barge which could take a week. That is time that you just do not have in palliative care.*¹⁴⁶²

15.3.1.4 Lack of specialist and general palliative care health practitioners

The QSPCSMDG highlighted issues with inadequate access to specialist palliative care in regional, rural and remote communities, stating:

*There are regional, rural and remote communities with no direct access to specialist palliative care. Clinicians in these places and their surrounds spend time ringing around the state to ask for specialist palliative care advice. Clearly, this make-do model is not sustainable and unfortunately adds further burden to already stretched palliative care services and leads to less than optimal patient outcomes and service delivery.*¹⁴⁶³

Dr Geoffrey Mitchell advised that another matter for consideration for rural and remote medicine is that hospitals in these areas are often staffed with people trained overseas. Dr Mitchell explains:

*We are talking about a very complex set of circumstances when we talk about rural and remote medicine—there is no doubt about that—and a lot of it is to do with the need to staff these hospitals with whomever is available. Some 50 per cent of the people who staff hospitals in regional areas are brought in from overseas and the nature of training in some parts where these people come from is fundamentally different to the type of training that we accept as normal in Australia. In developing countries it is all about acute medicine. It is about controlling someone's malaria or TB. We are about chronic disease. We have a western view of how end of life should be managed. If there has been no exposure to it and they are out there with not much support, how are they going to provide it? In fact, go back a step: how do you provide it? What should you be providing as a fundamental part of training these people before they are put in that situation?*¹⁴⁶⁴

Submitters to the inquiry offered solutions to alleviate the lack of specialist care. The QSPCSMDG called for investment in specialist palliative care services across 'all settings of care to provide coordinated, evidence-based, systemised, equitable and accountable care', available to the need of the community '24 hours a day, 7 days a week'.¹⁴⁶⁵

The PCQ submission made a number of recommendations to improve access to palliative care services:

- *Increase number of specialist palliative care doctors to 2 per 100,000 population.*
- *Increase the number of specialist palliative care nurse practitioners, specifically in regional and remote settings*
- *Ensure, in conjunction with the Queensland Nurses and Midwives Union, specialist palliative care teams have an adequate number of registered nurses, who should at a minimum have completed professional development activities in palliative care*
- *Each HHS requires a palliative care qualified clinical director overseeing the whole HHS*
- *Ensure all Specialist Palliative Care Services (Level 3, 2 and 1) have a funded holistic team*
- *To improve access to specialists in rural and remote areas, develop a 'Hub and Spoke' model with larger centres supporting more remote and rural areas, such as Townsville Hospital*

¹⁴⁶² Private briefing transcript, Brisbane, 23 January 2019, p 23.

¹⁴⁶³ Queensland Specialist Palliative Care Services Medical Directors' Group, submission 2681, p 2.

¹⁴⁶⁴ Dr Geoffrey Mitchell, Professor of General Practice and Palliative Care, University of Queensland, public hearing transcript, 5 July 2019, Brisbane, p 48.

¹⁴⁶⁵ Queensland Specialist Palliative Care Services Medical Directors' Group, submission 2681, p 6.

supporting Mackay, Mt Isa, Ingham, Ayr, Home Hill, Charters Towers, Richmond, Hughenden, and Palm Island areas, using existing Telehealth and other service delivery

- *Fund demonstration models of care that enhance specialist palliative care nurses to coordinate generalist (level 1) services in the community*
- *Expand interdisciplinary specialist palliative care (Level 2 and 3) services to cover the community – decreasing the number of admissions to hospital and decreasing the number of avoidable or unwanted admissions to hospital. Allow people to get care where they want. Build population’s capacity to look after their own.*¹⁴⁶⁶

15.3.1.5 Palliative nurses

The Queensland Nurses and Midwives union identified the need to establish support structures for palliative care nurses who ‘often have to practice in relative isolation in regional, rural and remote areas’.¹⁴⁶⁷

Dr Peter Whan addressed directly and specifically the role of palliative nurses:

The challenges are significant. I am not telling the committee anything you do not know. My United States colleagues have a hierarchy of regional, rural, remote and frontier—they tack on ‘frontier’. Some of the communities I have visited I would affectionately term ‘frontier’, not in the least in a pejorative way. Those communities call in their resources and in many cases provide an amazing level of care to their community members by pulling resources together. That is patchwork and variable again.

*Chair, you mentioned the vital role of nurses in this area. If I could make a plea: for the past 12 years I have been the only designated palliative medicine specialist for a population of about 400,000 people across a service area of about 200,000 square miles. On Palliative Care Australia workforce guidelines—two per 100,000—there should be eight of me. I would be absolutely useless if it were not for the wonderful advanced practice nurses who are there, boots on the ground, 365 days a year, who as members of their local community understand the particular issues, challenges and opportunities within the community. We need to do whatever we as a community can do to support those nurses—sometimes individual nurses, sometimes teams of nurses. As other members of the group have said, they often see to their own education. They enrol in graduate diplomas through Flinders University or whatever it may be. They are the key to the on-the-ground provision.*¹⁴⁶⁸

Carolyn Mandersloot, a specialist palliative care nurse working in rural Queensland, highlighted the important role of professional health practitioners to assist people to stay at home at the end of their life. Ms Mandersloot submitted:

In the large rural and often remote area I work in I know I always have colleagues, GP’s and Palliative specialists to call on if I have a question. We work as independent practitioners and often alone after hours, sometimes an hour’s drive from base in areas with no mobile coverage. We work with lay families with little to no experience but who have the will and love to care for their person and keep them at home. Part of the success of people staying at home to die is the support of the GP, the timely writing of scripts for medications to control symptoms, the time to educate and answer questions, the availability of equipment to aid care, the support of

¹⁴⁶⁶ Submission 1891, p 5. In text reference removed. NB: in-text references have been removed. Refer to original source for more information.

¹⁴⁶⁷ Submission 1213, p 29.

¹⁴⁶⁸ Dr Peter Whan, public hearing transcript, 5 April 2019, Brisbane, p 12.

*volunteers and community members to support carers and the opportunity for our nurses to be able to respond quickly as needed.*¹⁴⁶⁹

15.3.1.6 The use of telehealth and other innovative delivery methods

Telehealth technologies can provide a conduit to delivering better access to palliative care services to Queensland communities. The department outlined its telehealth palliative care services in its Palliative Care Services Review, in 2019:

Telehealth palliative care services are an emerging model, enabling an innovative and patient-focused service for palliative care patients to stay in their own homes while receiving specialist consultation via videoconference.

Typically, the model involves the patient being visited by a palliative care specialist nurse, who conducts all the required assessments such as blood pressure, pulse and pain assessments. The nurse brings a Queensland Health iPad, and the consultant dials into this iPad. The model supports a reduction in travel by clinicians and patients and facilitates a more efficient use of clinicians' time.

There are significant benefits to consumers, in addition to reduced travel times, including more opportunities to see their consultants and for their families to be involved during consultations.

In 2017-18, there were 1,872 non-admitted patient (outpatient) telehealth service events for palliative care reported across 13 HHSs, 58 percent more than in 2016-17.

*There were also 348 telehealth consultations for palliative care for admitted patients reported across Mackay, Sunshine Coast, Townsville, and West Moreton HHSs. These services were generally provided and received within a hospital or other health service setting.*¹⁴⁷⁰

According to St Vincent's Health Australia:

*... in a decentralised state like Queensland we need to make much better use of technology to deliver advice, support and services into regional and remote areas to support clinicians and service providers who are delivering end-of-life care within regional and remote areas.*¹⁴⁷¹

Dr Whan described the important role telehealth services provide assisting palliative specialists and nurses in rural and remote areas:

One of the roles I feel I have particularly provided for them—my title is outreach and support—is a support role in being a specialist medical colleague to those nurses and providing informal education and advice. I have been available by telephone and more recently via telehealth, with Queensland Health's wonderful telehealth infrastructure. I do not know whether committee members can recall the palliative care seminar when I stood up and talked about doing telehealth on my phone.

...

To be able to provide that support I think has been a key part of keeping those advanced practice nurses energised with a sense of support. If they do not get support from specialist palliative care services and multidisciplinary palliative care services, and especially access to specialist palliative medicine advice and support, they are tempted or pushed sometimes to work outside their scope

¹⁴⁶⁹ Submission E1100.

¹⁴⁷⁰ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 18.

¹⁴⁷¹ Mr Toby Hall, Group Chief Executive Officer, St Vincent's Health Australia, public hearing transcript, Brisbane, 4 July 2019, p 45.

*of practice which is not appropriate, and they do not want to do that. There are big challenges. There is a lot of goodwill in local communities. Advanced practice nurses have a vital role.*¹⁴⁷²

Telehealth services were also viewed as providing vital support to general practitioners, as Dr Willett attested:

*Often what the rural and regional GPs will need is actually someone to ring up when they get stuck because there are no palliative care physicians in those areas. When they get an unusual or difficult problem it is about having someone to consult with. That is a problem that probably cuts across a lot of outpatient referrals. Often GPs have a simple single problem and often the patients actually do not need to see one of our specialist colleagues. Often the telehealth situation, often just running the scenario by them and getting a couple of quick pieces of advice, is sufficient to deal with a lot of problems. It is an area that Queensland Health is working on expanding, but it would be great to see more of that shared care model in all sorts of areas, but particularly in palliative care and aged care.*¹⁴⁷³

Dr Andrew Broadbent of the QSPCSMDG advised the committee the Gold Coast HHS provides 60 to 80 telehealth sessions a month. Dr Broadbent spoke to some of the benefits of their telehealth services:

*It allows our senior clinicians, who are usually medical but are also senior nurses, to work with community nurses and other members of our specialist palliative care team, and we are about to roll it out to Queensland Ambulance on the Gold Coast—the first place in Australia—where, where they are concerned about patients who are known to our service, they can ring through for instant video advice within the usual five- to 10-minute range.*¹⁴⁷⁴

Professor Yates outlined some of ways telehealth services can address the challenges of delivering palliative services in regional and remote areas. She stated:

I think there are better ways in which we can network services—specialist services and non-specialist services—through the use of technology. There is good evidence out there, both in some small studies in Australia but also overseas, that shows that technology enables us to provide good outcomes. I think there is a lot more that we can do with telehealth—by using remote monitoring and connecting patients and their carers more effectively.

...

I think there is so much more potential around technologies that can apply to end-of-life care. I do not think that technology has been a space that people have really used. I think that is partly because people worry that it is not just a technical thing—If we start talking about technological solutions, are we going to take away the person-centred side of that?’ I do not think there is anything further from the truth. I think that goes to how you train our workforce to realise that that is the future of health and aged care. It is using technology, but it frightens people, because they think that you will take out the person side of things.

I cannot identify any specific examples of where there is great innovation except at the point of providing immediate information about patient needs—some of the technologies around understanding patients, patient reported outcomes and using patient reported outcomes through technological solutions to drive how we plan our care and how we bring in the right services. That is probably where it is happening the most but, in terms of things like how do we

¹⁴⁷² Dr Peter Whan, Queensland Specialist Palliative Care Services Medical Directors’ Group, Public hearing transcript, Brisbane, 5 April 2019, p 11.

¹⁴⁷³ Dr Bruce Willett, Chair, Royal Australian College of General Practitioners, Queensland, public hearing transcript, Brisbane, 4 July 2019, p 8.

¹⁴⁷⁴ Public hearing transcript, Brisbane, 5 April 2019, pp 5-6.

*lift people, how do we use the right equipment and devices, I think a lot more work could be done there.*¹⁴⁷⁵

The committee heard suggestions from a number of sources for a centralised access point to palliative services, available on a 24-hour basis.¹⁴⁷⁶ For example, Dr Good of the QSPCSMDG stated:

*...every palliative care patient should have access to specialist palliative care 24 hours a day, seven days a week. I am not saying that these examples are easy things to reach; I am saying that they are really high-standard things. That does not necessarily mean face-to-face after hours. It could be through telehealth. It could be by telephone. People do not have access to this at the moment.*¹⁴⁷⁷

Catholic Health Australia suggested a similar centralised service:

*The current model of non-specialist physicians providing PC can be improved by enabling 24hr access to specialist consultancy services for physicians to seek advice.*¹⁴⁷⁸

Mr Toby Hall of St Vincent's Health Australia described to the committee his organisation's remote support services and observed benefits:

We actually run a statewide 24/7 service in Victoria to regional and rural areas to support providers, families and clinicians in those communities, so we have very good experience in that field... in regional areas, there is absolutely that capacity to provide clinician-to-clinician 24/7 coverage to support people who are in the field who have an emergency at some point in time to understand how to treat someone in the home. That is absolutely key because a number of family members and clinicians are absolutely able to support family members in the home in regional areas. However, there is this fear and doubt of, 'What happens when something goes wrong? What do I do?'

In a clinician-to-clinician peer model we actually provide support to those clinicians from a palliative care expert 24/7. They can call at three in the morning and say, 'Oh my goodness, this is happening. Can you tell me what to do?', and we will step them through, either via telephone or videoconferencing, exactly what to do. That kind of service is absolutely replicable across Australia—in fact, it should be in place across Australia. We have the technology to do that quite easily. However, it needs to come with the training programs for those practitioners so they know how to respond in general and then when they have very complex issues, they can access us.

*Interestingly enough, what we found through that is when that is in place, the capacity in that local community and the confidence to deliver in-home services go up very, very quickly because the fear is taken away. What it is replicated with is an understanding and knowledge that 'if there is a problem I can always get an answer'. When people know that, family members and providers are much more confident and it works much better.*¹⁴⁷⁹

The QSPCSMDG called for 'a specialist digital palliative care solution to benefit palliative care patients across Queensland'.¹⁴⁸⁰ The group described the basis for this solution as follows:

Specialist Palliative Care services currently struggle with real-time information sharing and data capture. In Queensland integrated electronic medical records (ieMR) currently stops at the

¹⁴⁷⁵ Professor Patsy Yates, Deputy Vice-Chancellor and Vice-President (Research and Innovation), Queensland University of Technology, Public hearing transcript, Brisbane, 5 July 2019, p 40.

¹⁴⁷⁶ Queensland Specialist Palliative Care Services Medical Directors' Group, submission 2681, pp 1, 6.

¹⁴⁷⁷ Dr Phillip Good, QSPCSMDG, public hearing transcript, Brisbane, 5 April 2019, p 12.

¹⁴⁷⁸ Submission 1249, pp 7-8.

¹⁴⁷⁹ Mr Toby Hall, Group Chief Executive Officer, St Vincent's Health Australia, public hearing transcript, Brisbane, 4 July 2019, pp 48-49.

¹⁴⁸⁰ Submission 2681, p 7.

*hospital door and is in its generic phase rather than fit for purpose. Community specialist services have to depend on multiple piecemeal solutions to capture patient information, consistent outcome data and jurisdictional activity data. The ability to mine aggregated relevant inputted palliative care data from a fit for purpose digital solution would allow services, the system and the community to be informed of current and evolving patient needs into the future and the requirements for service to be optimised.*¹⁴⁸¹

The submissions of Queensland Primary Health Networks and Palliative Care Nurses Australia supported the use of emerging technologies to provide better and more equitable palliative services across Queensland. Palliative Care Nurses Australia stated:

*New models need to incorporate use of technologies to be able to link specialist palliative care clinicians with regional and remote generalist trained health services and clinicians. Models should address the needs of regional Queenslanders whose care requirements may not be met within a single hospital and health service boundary. Focus should be on the person not place of residence.*¹⁴⁸²

The submission of Queensland Primary Health Networks recommended:

*Better funding models, infrastructure (i.e. telehealth) and innovative models of specialist palliative care to support Queenslanders living in rural and remote locations to receive the majority of their care in their community if this is what they choose.*¹⁴⁸³

15.3.2 Access to palliative care for vulnerable cohorts

The committee heard that particular groups within society may also face particular challenges with accessing palliative care services, including people from culturally and linguistically diverse (CALD) cultures, Aboriginal and Torres Strait Islander peoples, children/young people, and other groups such as those who identify as lesbian, gay, bisexual, transgender, queer (or questioning), and intersex (LGBTQI).

In regards to future palliative care needs of vulnerable cohorts, The Anglican Church Southern Queensland (ACSQ) submitted that there is:

*...a distinct lack of palliative services and access for the marginalised in our community and those with specific needs – including the homeless (around 20,000 people in Queensland – many in poor and deteriorating health), the LGBTIQ community, those suffering from mental illness, refugees and former prisoners; as well as those requiring greater cultural sensitivity and capability from carers and service providers, including...Aboriginal and Torres Strait Islander peoples.*¹⁴⁸⁴

The ACSQ noted the need for diverse palliative care options and called for urgent funding of hospice care, which can:

*..offer a meaningful and important space to negotiate complex end of life concerns about identity, relationships and what it means to have a ‘good death’, away from the medicalised environment of a hospital or the stresses and tensions of in-home care by family members.*¹⁴⁸⁵

¹⁴⁸¹ Submission 2681, p 7.

¹⁴⁸² Palliative Care Nurses Australia, submission 1305, p 3.

¹⁴⁸³ Submission 1301, p 10.

¹⁴⁸⁴ Submission 1229, p 11.

¹⁴⁸⁵ Submission 1229, p 12.

15.3.3 Access to paediatric palliative care services

During the inquiry, the committee heard about the particular need for, and delivery of, paediatric palliative care services in Queensland.

Queensland Health advised that ‘estimates for paediatric palliative care services indicate between 2,700 to 4,090 children in the Queensland population under 19 years old could require palliative care services’.¹⁴⁸⁶

The submission from Hummingbird House stated that there are at least 1,200 children with chronic and complex needs living with a life-limiting condition in Queensland and Northern New South Wales. Hummingbird House estimated that approximately 20 to 30 percent of these children will require a ‘degree of support from a specialist palliative care team’.¹⁴⁸⁷

Ms Michelle Garner, Executive Director of Nursing Services at North West Hospital and Health Service, noted the importance of paediatric palliative care, and some of the challenges faced by communities in accessing these specific services:

*The other thing I wanted to say about palliative care is that we have forgotten about our kids. We have a number of children who go into palliative care. We have babies who go into palliative care. We have a great connection with the Children’s Hospital in Brisbane. They provide telehealth palliative care services. They are few and far between—there are not a lot of them—but for families it is crucial that we get those kids back to where they live with their families, not to dislodge the family entity in how they are living but to get those kids back here to be fully supported in their palliative care journey. For some of these kids it can be a very long time. We do have a dedicated service in Mount Isa that is connected with the Children’s Hospital and funded by the Children’s Hospital. That is a nursing position that provides chronic care for children who need it. When we get into that palliative care phase for children, it does become quite challenging.*¹⁴⁸⁸

The committee heard of the work of the Paediatric Palliative Care Service (PPCS), which is attempting to address some of these challenges. The PPCS is a Queensland Statewide service which looks after families of children with life-limiting conditions who are not expected to reach adulthood. The committee heard from Ms Lee-Anne Pedersen, a Nurse Practitioner at PPCS, who provided information about how the service operates:

*This service certainly supports the families, the healthcare providers and the communities across the whole state to care for the child with palliative care needs, particularly at end of life, in that location of choice. This holistic approach with the local teams and communities results in the best preparation for the family’s long bereavement road ahead of them. All of our combined care helps the families live with the loss of their child going forward. Ideally, it helps the families to continue to be productive members of the community with good physical health, good mental health and cultural and economic safety. We are certainly all responsible for the care of these community members.*¹⁴⁸⁹

PPCS noted that the number of children requiring palliative care is increasing.¹⁴⁹⁰

Ms Pedersen highlighted some of the challenges faced, particularly in regional and remote areas:

¹⁴⁸⁶ Queensland Health, correspondence dated 23 January 2019, *Briefing on aged care, palliative care and legal documents relevant to end-of life care in Queensland*, p 22.

¹⁴⁸⁷ Submission 1292, p 9.

¹⁴⁸⁸ Public hearing transcript, Mount Isa, 31 May 2019, p 6.

¹⁴⁸⁹ Public hearing transcript, Brisbane, 4 July 2019, p 47.

¹⁴⁹⁰ Public hearing transcript, Brisbane, 4 July 2019, p 51.

*We are working alongside a lot of care providers who are not paediatric orientated at all. As soon as you leave the south-east corner, you often do not get a paediatrician. You certainly do not get anybody with paediatric palliative care experience—unless they have seen us before. To then support an away team means that the expertise from here goes alongside with role models and teachers in time. We know that the literature tells us that in-time training, on the spot, related to a case is the best way for health professionals to learn.*¹⁴⁹¹

As part of addressing these challenges, the PPCS offers 24-hour phone support. Ms Pedersen explained:

*Currently, we offer a 24-hour toll-free phone line...It is a collaborative project that works across all the other six national paediatric palliative care specialist services to reach out. Regardless of the child's geographic position, we can make sure that we are providing some education to some of these away centres. South Australia and Queensland are servicing the Northern Territory. Melbourne is servicing Tasmania.*¹⁴⁹²

15.3.3.1 Hummingbird House

Hummingbird House, Queensland's only children's hospice, was established following a recommendation of the Health and Community Services Committee 2013 inquiry into Palliative Care Services in Queensland. The report identified a specific gap in services for children with a life limiting condition.¹⁴⁹³

According to its submission to the inquiry, Hummingbird House is:

...a community hospice service, which has a state wide reach. This service is comprised of a 9-bed licensed private healthcare facility (8 guest-in-care suites, and one purpose built suite for after death care) based in Chermside, family support, creative therapies, allied health, and community outreach for clinical and family support service delivery. Hummingbird House is fully accredited under the National Safety and Quality Health Service Standards. Wesley Mission Queensland is the clinical operator for HH.

*Within the Clinical Skills Capability Framework (CSCF) Hummingbird House provides state-wide hospice care for children who are likely to die before the age of 21, within the facility, or within the child's home.*¹⁴⁹⁴

Hummingbird House advised that since opening in 2016, it had provided in-hospice or in-home care at end of life for over 52 children and their families.

In regard to meeting the current needs of children/young people, Hummingbird House stated that in Queensland each year 'there are approximately 400 children with life-limiting disorders who would be considered particularly fragile, and at risk of dying within the next 12 months'.¹⁴⁹⁵

In regard to improving palliative care and end-of-life services for children and young people in Queensland, Hummingbird House advised:

As Queensland's only children's hospice, Hummingbird House has a remit to provide palliative care in both the facility at Chermside and within the child's home, no matter where in Queensland they live. Currently, this arm of the service is still being developed and relies very heavily on community fundraising. This arm will see staff fly/drive to the child's community to provide in-

¹⁴⁹¹ Public hearing transcript, Brisbane, 4 July 2019, p 51.

¹⁴⁹² Public hearing transcript, Brisbane, 4 July 2019, p 50.

¹⁴⁹³ Health and Community Services Committee, *Palliative and community care in Queensland: toward person-centred care*, Report No. 22, May 2013, p 38.

¹⁴⁹⁴ Submission 1292, p 2.

¹⁴⁹⁵ Submission 1292, p 10.

home respite care, family support, and grief and bereavement support to the entire community. By travelling to the child's community, we can extend the child and family centred care HH offers outside of the south-east corner.

Working closely with Queensland Children's Hospital, other paediatricians and other clinical staff in regional centres, this outreach model of care will help ensure equitable access to child and family focussed palliative care and provide choice regarding the nature and location of end of life care. This results in prudent use of financial, as well as clinical, resources and supports families in the community where they live and grieve.

*There currently exists a major shortfall in the provision of a state-wide service. This applies to every component of paediatric palliative care: from respite, care at end of life through to grief and bereavement support. These aspects of care are not permanently funded, aside from modest funding support for PPCS and at present, there is no prospect of this changing. There also exists a major lack of access for in-community care and neonatal service for all communities throughout Queensland.*¹⁴⁹⁶

In addressing the challenges of distance, Hummingbird House stated:

The need for a 'bricks and mortar' facility has been met with the building of Hummingbird House. It is now planned that this facility will be the hub for a 'spoke and hub' model of care around Queensland.

*This is a model which arranges service delivery assets into a network consisting of an anchor establishment (hub) which offers a full array of services, complemented by secondary establishments (spokes) which offer more limited service arrays. The Family Support and Clinical teams are both committed to an outward-looking, community-based model of care, which seeks to utilize and develop capacity within existing networks, rather than unnecessary duplication of service.*¹⁴⁹⁷

15.3.4 Access to palliative care for Indigenous Queenslanders

Aboriginal and Torres Strait Islander people have different health profiles and rates of death to other Queenslanders and this affects their demand for palliative and end-of-life care.

The most recent published statistics comparing Indigenous and non-Indigenous persons' rates of hospitalisation for palliative care services found that:

*In July 2013 to June 2015 in Queensland, the age-standardised rate of hospitalisation for palliative care for Indigenous Australians was 3.3 per 1,000. This was 1.6 times the rate for non-Indigenous Australians (2.0 per 1,000). The rate for Indigenous males was higher than the rate for Indigenous females (3.9 compared with 2.9 per 1,000). The rate for non-Indigenous males was higher for non-Indigenous females (2.4 compared with 1.7 per 1,000).*¹⁴⁹⁸

This higher rate of palliative care hospitalisation for Queensland's Indigenous peoples can be viewed as part of the continued variance in health outcomes experienced by Indigenous and non-Indigenous peoples. The Australian Institute of Health and Welfare have stated that:

Indigenous Australians have significantly poorer health status than non-Indigenous Australians. Inequalities in health care access and use may further exacerbate inequalities in health status.

¹⁴⁹⁶ Submission 1292, p 12.

¹⁴⁹⁷ Submission 1292, p 13.

¹⁴⁹⁸ Australian Institute of Health and Welfare, *Aboriginal and Torres Strait Islander Health Performance Framework 2017 report*, Queensland, p 142.

*As a result, access to health care when needed is essential to closing the gap in life expectancy.*¹⁴⁹⁹

Since 2008, Australian governments have committed to delivering better health, education and employment outcomes for Aboriginal and Torres Strait Islander peoples, in an effort to close the gap that exists between Indigenous and non-Indigenous Australians.

In Queensland, the life expectancy gap between Indigenous and non-Indigenous peoples remains at 7.8 years for males and 6.8 years for females.¹⁵⁰⁰ In relation to this, Queensland Health state:

The three leading drivers of this life expectancy gap between Aboriginal and Torres Strait Islander and other Queenslanders, which together explain over half of the gap are:

- *Cardiovascular disease – an estimated 21% of the gap for males and females*
- *Cancers – an estimated 20% of the gap for males and 18% for females*
- *Diabetes – an estimated 13% of the gap for males and 18% for females.*¹⁵⁰¹

Figures from the Palliative Care Outcomes Collaboration (PCOC) state that the average age of palliative care episodes for Aboriginal and or Torres Strait Islander peoples in Queensland in 2018 was 10 years younger than for non-Indigenous persons. For Indigenous persons, the average age that they experienced palliative care was 61.6 years as compared to 71.7 years for non-Indigenous peoples. When looking further at the age groups of palliative care episodes, a much greater proportion of Indigenous peoples experience palliative care when they are aged under 50 years old (22.3%) than non-Indigenous peoples do (6.6%).¹⁵⁰²

The 'Queensland Health Palliative Care Services Review – Key Findings' noted that:

*Aboriginal and Torres Strait Islander Queenslanders experience a disproportionate burden of disease compared with others. The death rate for Aboriginal and Torres Strait Islander Queenslanders was 49 percent higher than the rate for non-Indigenous Queenslanders after accounting for differences in age between the two populations.*¹⁵⁰³

St Vincent's Health Australia advised the committee that:

*As in other areas of health, Aboriginal and Torres Strait Islanders are extremely disadvantaged in comparison to the wider population when it comes to access to palliative care services and end-of-life services. That is even more challenging in the most remote areas of Queensland.*¹⁵⁰⁴

¹⁴⁹⁹ Australian Institute of Health and Welfare, *Aboriginal and Torres Strait Islander Health Performance Framework 2017 report*, Queensland, p 142, <https://www.aihw.gov.au/getmedia/0912908c-a8df-4c94-8629-460d5f69784a/aihw-ihw-184-qld.pdf.aspx?inline=true>.

¹⁵⁰⁰ Department of Aboriginal and Torres Strait Islander Partnerships, *Queensland Closing the Gap Snapshot Report Card 2019*, p 3, <https://www.datsip.qld.gov.au/resources/datsima/programs/closing-gap/ctg-snapshot-2019.pdf>.

¹⁵⁰¹ Queensland Health, *Closing the Gap in Queensland* (Aboriginal and Torres Strait Islander Health Branch), https://www.health.qld.gov.au/atsihealth/close_gap.

¹⁵⁰² Palliative Care Outcomes Collaboration, *Palliative care at a glance in Queensland web report*, Table 10 Palliative care episodes of care by age group and Indigenous status, Queensland, 2018, <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow259482.pdf>.

¹⁵⁰³ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 23.

¹⁵⁰⁴ Toby Hall, Group Chief Executive Officer, St Vincent's Health Australia, public hearing transcript, Brisbane, 4 July 2019, p 46.

15.3.4.1 Resourcing of palliative care in Indigenous communities

The committee heard throughout the inquiry of palliative care across Queensland being under-resourced in relation to current demands. This situation is exacerbated in rural and remote areas of Queensland where Indigenous populations are proportionally higher.

Mr Stephen Christian, the Palliative Care and Aged Care Project Officer, NPA Family and Community Services Aboriginal and Torres Strait Islander Corporation, advised the committee that:

... the only palliative care service that exists north of Cooktown, and it is home care, is located at Bamaga. I am the only one who is working within palliative care. We are supported by and we interact very closely with Queensland Health through Bamaga Hospital. For medical advice, direction and support, my nearest access point is the specialist physician consultant in palliative care medicine here at the Cairns Hospital. Other than that I am it, interacting with Queensland Health through Bamaga Hospital, getting advice and direction either through the organisation and/or the specialist physician consultant.

Despite the fact that many locations in the cape, including Thursday Island—and I have done a trip out to the eastern islands of the Torres Strait—want some support in palliative care, at that point in time I could only set them in the direction that they needed to go in relation to support, support systems and processes. At the moment, given the lack of resources, my jurisdiction lies within the five communities of the Northern Peninsula Area. That saddens me, because they are reaching out for help. At this point in time, I am unable to assist them other than to give them general directions.¹⁵⁰⁵

Palliative Care Queensland (PCQ) stated in their submission that:

There is no Specialist Palliative Care Service available in the Torres Strait Islands. PCQ is aware of visits by PEPA [The Program of Experience in the Palliative Approach] Queensland involving palliative care nursing and medical staff, including Dr Edward Mantle, palliative care physician from Cairns and Hinterland HHS, and Prof Janet Hardy, Director of Palliative and Supportive Care at Mater Health Services Brisbane. PEPA has recently conducted visits to Torres Strait to educate the community and Aboriginal and Torres Strait Islander Health Workers about palliative care. PEPA has been successful in encouraging Health Workers to experience clinical observational placements with specialist palliative care teams in Cairns and Townsville, though numbers are relatively small.

In Cape York, a collaboration between St Vincent's Health Australia and NPAFACS (Northern Peninsula Authority Family and Community Services) has delivered some palliative care education and services. Palliative Care Queensland is also undertaking a project, funding by Queensland Health and Cook Shire Council to scope the development of a multipurpose end-of-life care centre.¹⁵⁰⁶

15.3.4.2 Further cultural considerations and challenges

In addition to these funding and resourcing issues, PCQ advised:

Some of the particular challenges of delivering palliative and end of life care for Aboriginal and Torres Strait Islander communities include:

- *A belief that talking about death, dying, and end of life will attract it into one's life*
- *The belief by some in the community that illness and death is caused by sorcery and not by natural causes*

¹⁵⁰⁵ Public hearing transcript, Cairns, 28 May 2019, p 4.

¹⁵⁰⁶ Submission 1891, pp 54-55.

- *Mistrust of the health system because of the part it has played in the past in oppression of Aboriginal and Torres Strait Islander peoples*
- *Language differences – for some people, English is their third or fourth language, and they might have little understanding of what is being said to them by health care professionals*
- *Some health care professionals lack cultural sensitivity, engendering distrust on the part of the Indigenous community.*¹⁵⁰⁷

These points were reiterated by some of the Indigenous persons who met with the committee. For example, on Palm Island, Councillor Deniece Geia of the Palm Island Shire Council said that ‘Indigenous people—do not like to talk about death and dying. That is bad luck’.¹⁵⁰⁸

In Mossman, Ms Janice Walker outlined her experiences of visiting Indigenous peoples in hospitals and seeing cases of what she said were neglect and disrespect:

*I had seen it over and over again in hospitals where our people do not receive explanations about the medical condition of their family member lying there... I brought it back to respect. You do not just leave a man dying there and not tell the family that is gathered around there what is wrong with him or how long he has.*¹⁵⁰⁹

Queensland Health acknowledges these issues as well:

*Aboriginal and Torres Strait Islander people may have a general feeling of distrust of non-Indigenous health staff. This may be due to historical factors, or possibly feelings of being judged or being treated unfairly in unfamiliar environments, such as mainstream health services.*¹⁵¹⁰

Mr Stephen Christian said:

I can only say that out of this inquiry we are hoping that not only recognition but also supports are put in there. I am not just talking about money. It is about any and everything that supports one to support the client or the patient. I prefer ‘the individual’, because when dealing in palliative care it is not just that individual. As everybody around the table here knows, you are actually supporting the person, the family, the community.

*... When many of our family members are suspicious of a certain health condition, be it through the complications of a chronic disease—generally renal—complications of diabetes or a suspicion that somebody may have a cancer of a certain type, further investigations are usually undertaken in Cairns or, in some situations, they have ended up in Townsville. We have had quite a few who have had further investigations in Brisbane and the diagnosis was not very good at all. That added a whole lot of pressure onto the individual and the families. Then it is about really coming back home, because the outcome is very sad.*¹⁵¹¹

15.3.4.3 Displacement during treatment and the costs incurred

On Palm Island, Ms Daphne Cummings spoke to the committee about the costs involved with having to travel to access palliative care services:

I see the importance of palliative care as we live remote. Families have to travel to Townsville, and that costs money—accommodation fees, bus fares, taxi fares and what have you—to spend

¹⁵⁰⁷ Submission 1891, p 55.

¹⁵⁰⁸ Public hearing transcript, Palm Island, 30 May 2019, p 8.

¹⁵⁰⁹ Public hearing transcript, Mossman, 28 May 2019, p 7.

¹⁵¹⁰ Queensland Health, *Sad News, Sorry Business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying* (version 2), December 2015, p 6.

¹⁵¹¹ Public hearing transcript, Cairns, 28 May 2019, p 4.

*time with family in their last days in Townsville at the hospital. I see those as challenges for our mob.*¹⁵¹²

Palliative Care Queensland noted in their submission that they were:

*...aware of the significant dislocation of families and elders to Cairns and Townsville when patients are sent there for treatment towards end of life, but the person deteriorates and is unable to come home before their death, therefore reducing their ability to share their legacies, traditions and stories.*¹⁵¹³

St Vincent's Health Australia's submission also addressed the issue of Indigenous peoples needing to travel large distances to access palliative care:

The key principle of delivering palliative and end of life care is it should be person-centred and take into consideration the cultural needs of patients. One of the major challenges in Queensland is remoteness and access. For example, for communities in Cape York, the closest palliative care services are in Cairns, some 1000kms away. For people living in the Northern Peninsula Area's five communities who have a life-limiting illness, accessing end of life care often means leaving the community, family and country to travel to Cairns.

*With some of the highest levels of chronic disease in the country and an average life expectancy of 58 years, there's considerable need for high-quality and culturally appropriate end of life care across the Cape York and Torres Strait regions.*¹⁵¹⁴

15.3.4.4 Life is a part of a greater journey

In regards to caring for Aboriginal and Torres Strait Islander people during end-of-life, Queensland Health has advised their staff that:

*In the lead up to an expected death, there is usually a gathering of immediate and extended family and friends. This will likely take place at the family home but hospital staff should anticipate a large number of visitors to see the patient. Groups may also congregate in the hospital or nearby. Based on the belief that life is a part of a greater journey, it is cultural practice to prepare the person for the next stage in their journey. The gathering is a mark of respect for the patient.*¹⁵¹⁵

The committee heard of the importance of having hospital and hospice wards with adequate space to accommodate family and friends of Indigenous palliative care patients and the need for visiting hours to be flexible.

Ms Tammie Harrison, Senior Project Officer, Department of Aboriginal and Torres Strait Islander Partnerships advised that 'We visit at all hours, all day. ... not nine to five, Monday to Friday'.¹⁵¹⁶

Councillor Geia told the committee:

It is not just having placemats with Aboriginal designs. That is good, but we want to go that step further. From the experience that I had with my old dad, we should be allowed to have everybody sit around and be at palliative care. Do not make the wards tiny, because we have a big mob. When we want to go and visit someone and maybe they do not have long now, everybody turns up. People are everywhere and there are cars everywhere at the hospital, because everyone will go and pay their last respects and say their goodbyes. Let the dog come in. That is what I am

¹⁵¹² Public hearing transcript, Palm Island, 30 May 2019, p 1.

¹⁵¹³ Submission 1891, p 55.

¹⁵¹⁴ Submission 1280, p 23.

¹⁵¹⁵ Queensland Health, *Sad News, Sorry Business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying* (version 2)', December 2015, p 10.

¹⁵¹⁶ Public hearing transcript, Palm Island, 30 May 2019, p 3.

*talking about—those types of things. If he wants that can of beer, let him have a drink before he goes. Bless him, they did that to my brother at the Townsville Hospital. If they want the fish soup and the damper, let them eat it. Do not be strict with your Queensland Health menu, which is rubber, anyway. If they want that scone, if they want turtle and rice—if they can eat, but I mean even before those last minutes while they are in there. That is the cultural appropriateness I am talking about. Let them eat there. Let people sleep there. If the dog wants to come in there, let it. Do not say, 'You can't come in. You go outside.' People need to be trained up for our mob. That is what I believe a palliative care unit should look like where it is welcoming, it is comfortable, it makes you feel really good and when you go there you are welcome. ...some nice Aboriginal didgeridoo music playing in the background, just giving a sense of, 'When you go, we are all here. You are not going to go alone.' That has been the pain, too. My journey personally was I was there with my dad every weekend. Then I came back on the Monday morning for work and he passed away two hours after I got back here. I said, 'Why did you do that? You should have just'—I was so angry with myself and then with him in part. He died alone. That is what really hurt me. I am getting a bit emotional now. He died alone. If it happens here on Palm, then all the mob would come and we can sing them through, clap them through or whatever: 'You're now alright.' ... 'You are not alone. Go in there. See you on the other side. Say hello to the family on that side.' That is the type of cultural appropriateness I would like to see with our mob in palliative care.*¹⁵¹⁷

Ms Tammie Harrison further explained:

*I am actually from Cherbourg. My uncle was in palliative care at Christmas time. He moved from Caboolture to come back home for his last few months. He actually moved back to Cherbourg. They had a palliative care in Wondai, which is about 20 kilometres away. It is very clinical: they are only allowed one or two visitors at a time. It was not culturally appropriate or anything like that. He loves his animals. Cherbourg actually put in a separate space attached to the hospital as a palliative care unit. There was a huge, big room with an ensuite and a lounge and they let family come and go as they pleased. They had a kitchen space there. We cooked meals there for him. He had his animals at the back. There was a little space as well. It was a really nice, culturally safe space.*¹⁵¹⁸

Mr Stephen Christian advised of other aspects of cultural sensitivities that health service providers needed greater awareness of in their palliative care treatment of Indigenous peoples:

... you have to be careful who you are talking to and how you are addressing certain matters. Having a basic understanding of certain people's totems and things helps. I have constantly ended up in arguments with doctors saying, 'What are you doing? He is going into spasm,'... I have said, 'No, no, no, you are interfering with the dying process. This person is enacting their totem. Leave them alone,' because as soon as they start to react, which is what you understand to do in your practice in western medicine—you have cultural medicine and western medicine—all you want to do is stab, poke and prod. That is not what it is about.

*You need to take a step back, get advice from other people who have an understanding of cultural practices and take it from there. I am glad to say that the GPs within Queensland Health are now appreciating and understanding more now, but they have a long way to go when it comes to end of life for Aboriginal and Torres Strait Islander people in Far North Queensland because it is not as straightforward as western medicine practices; they are just full steam ahead. There are things that you need to take into account.*¹⁵¹⁹

¹⁵¹⁷ Public hearing transcript, Palm Island, 30 May 2019, pp 8-9.

¹⁵¹⁸ Public hearing transcript, Palm Island, 30 May 2019, p 3.

¹⁵¹⁹ Public hearing transcript, Cairns, 28 May 2019, p 5.

15.3.4.5 *The importance of returning to country*

Queensland Health acknowledges the cultural importance of returning to country and have advised their staff that:

*Aboriginal and Torres Strait Islander patients may request to return to their homelands and to be close to their family and country for the final stages of their life. This is an understandable request; however, it may be complicated if the patient is on chronic therapy such as renal dialysis, or receiving palliative care. The desire to return to country will be more important to them than treatment of their disease.*¹⁵²⁰

Dr Brogan advised the committee:

... Aboriginal and Torres Strait Islanders and other people from other islands as well want to be with family. When I ask them what is most important to them often it is being connected and being around family that they know and love and understand them. That is often even more important than their level of comfort. They will at times put that as No.1 which means they do not get access to services that are available to other people in the cities. They feel often uncomfortable in the major hospitals and find it difficult to identify their needs at times and this is where our Indigenous liaisons and health workers and officers are really helpful in helping them have a voice. Many of them just don't want to come to hospital and so their health gets neglected and their symptoms get quite severe.

*When you have the opportunity of finding out what they want, always it is being home on country with people who know and love them and have the ongoing caring relationships with them too. This is where we are trying to enable the local clinicians to develop the confidence and the knowledge and the skills to be able to care for people with early on symptoms and even more complex symptoms so that people truly do have a choice to stay on country. If there is a real need for them to go to a tertiary service it is really important that those needs are recognised and the need for returning to country early enough is recognised. Sometimes that does not happen and they end up dying away from country or being sent back the night before, which is just not good for anyone.*¹⁵²¹

Ms Shyla Mills, CEO of PCQ, reiterated this, saying that the current approach is ‘disconnecting our first Australians in the Torres and the Cape from their communities ... and limiting their opportunity to die on country’.¹⁵²²

However, the committee heard one story where significant efforts were made in regards to respecting the cultural wish to ‘die on country’. Ms Lee-Anne Pedersen, Nurse Practitioner, Paediatric Palliative Care Service, advised:

Recently, we sent an Indigenous baby back to Dalby, because that was very important. They needed to be home to country. Dalby would never take on such a sick baby. However, that comes with a package of support. The team from the specialist palliative care team work with the family and the retrieval service, because sometimes we need their help when children are just so sick they require ventilation and support to get them back to where they want to be in the best condition they can be. We make decisions about the destination—do they want to be in the hospital, at home, or outback? We were under the tree with the mob—that is how it played out—and it was picture perfect.

¹⁵²⁰ Queensland Health, *Sad News, Sorry Business: Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying* (version 2)', December 2015, p 4.

¹⁵²¹ Private briefing transcript, Brisbane, 23 January 2019, p 19.

¹⁵²² Private briefing transcript, Brisbane, 23 January 2019, p 18.

*For the long-term health of that family, that was the best scenario. We role modelled behaviour to the local staff so that they could see clinically how to manage the child's condition so that he was very comfortable, he was not distressed. We set that up for the best outcome. That local community is suffering a terrible loss. However, going forward, they are going to be in the best order they can be because it was all on their terms—on their territory, spiritually safe; great. That funding model that we have currently to provide that is just absolute gold. That is changing the landscape a lot.*¹⁵²³

In Mount Isa, the committee heard about assistance given to patients there to return to country. Michelle Gerner, Executive Director, Nursing Services, North West Hospital and Health Service, said:

We do palliative care across the region. We will get patients who will want to come back to country. They will come from the coastal areas of Cairns, Townsville and Mackay. They may have been living in those areas for many years but they want to come back to country to finish their palliative care. We coordinate between all of us—with Gidgee and everybody—and set the ball rolling and get the patient back and we support them.

*It gets challenging in some of the remote communities, particularly around that management of pain relief. With some patients, particularly in remote communities and Indigenous communities, we will sometimes bring the patient in to the hospital overnight so that we can maintain their services.*¹⁵²⁴

The committee also heard of complicating issues that can prevent an Indigenous patient being able to be helped to return to country. Miss Loata Webber, Health Service Manager, Gidgee Healing Health Services, explained:

... the issue that I have come across in the last three cases is that they had a plan and they wished to go back to country, die on country, but when they were here in Mount Isa the problem we were facing was support at home. Two out of the three had no support at home. You can have all of those wishes, but if you do not have family or anyone at home to be taking care of you, to be monitoring you 24/7, it does not work. We need to look at those plans and say, 'If there is no-one at home because you are that sick that you need to have somebody with you to watch you, to make sure that you are taking your medication, that you are showering and that you are eating—all of that—it does not work.' It just doesn't. It gets thrown out the window.

Two out of three patients could not get their wish because they did not have any home support at all. That was a big issue. We had to battle that for another seven months. What are we going to do, because their wishes were to go back to country or to go home and die at home but there was no family? We spent a lot of our time trying to track down family and doing case conferencing between palliative care and other services, as well as Gidgee.

From our mob's perspective, the majority of them do have family there, but just in the last 12 months with three palliative patients we could not go with their wishes. Unfortunately, they had to die in hospital. That is the heartbreaking thing. Probably the majority of our community members out there can plan ahead. We already talk about that in chronic care: 'What are your plans? What do you want to do?' We bring in their guardians and their carers and ask: 'Have you had this discussion with family? What is it that you want to do?'

Like I said, I have not got to a point yet where we have had a situation where everybody is there—the full support from family to services. From what I have gone through in the last 12 months, that is what I see as a struggle for some of the families, especially if they have been taken out of country to Mount Isa and then not been able to go back to country. They do not want to be in hospital in Mount Isa. They want to stay out of hospital, but you cannot convince them that that

¹⁵²³ Public hearing transcript, Brisbane, 4 July 2019, p 51.

¹⁵²⁴ Public hearing transcript, Mount Isa, 31 May 2019, p 4.

is not the best choice. I have had only one patient that we could get back to country. That is one good news story out of three.

*If we plan for it and they have really good family support, it will work. Unfortunately, two patients had family and then all of a sudden nobody wanted to know anything. From an Aboriginal and Torres Strait Islander family perspective, for some of them it will work and for some of them it will not.*¹⁵²⁵

15.3.4.6 Deceased transportation costs

The matter of cost and cultural appropriateness of returning a person back to country for burial and cultural sorry business was raised. A figure of \$14,000 was provided. Mr Christian said:

The sad thing about that is that there are two ways your body can you shipped up. It is considered freight, which offends many of the family members, because that is all you are: cargo, or freight. Many have passed away in Brisbane. There is a specially designed van where you are frozen in Brisbane—snap frozen—you are packed and then it is an overnight journey from Brisbane to Cairns to the funeral director of your choice. It is another cost that you have to look at to get them back home up north, or they put you on a plane and that freight price doubles straightaway from Brisbane, or Townsville, to Cairns. Then you have to get the deceased from Cairns to whatever remote location or community.

The other thing that saddens me also is what families are starting to do. As painful as it is, they do not have a choice. They cannot afford it. They lay them to rest at whatever place where they pass away. Usually, they can get them to Cairns, so it is Cairns. We are starting to see now as a cost-saving exercise—and it is really culturally inappropriate—the numbers are slightly starting to increase where families have decided to have their loved ones cremated. That is a no-no. However, cost impacts everybody.

*We even tried to encourage people to go on funeral plans. Unfortunately, that has been taken advantage of by certain companies. They put them on a funeral plan and it just does not fit. It is not the right plan. Families have been caught out when a loved one has passed away. They were not able to access the money as they would have expected. ... Unfortunately, certain companies had taken advantage of people within remote areas and families have truly lost out.*¹⁵²⁶

Councillor Geia raised the issue of these costs as well:

*... when thinking about losing a loved one in Townsville in palliative care, there is the cost then because everyone wants to go into town because they are there alone and they probably move them to the morgue, so then the stress kicks in with regard to trying to get plane tickets and trying to get money and get to town straightaway. Some of us do not have families in Townsville either. Everyone is here. ... They sit at the morgue and then the funeral parlours go and pick them up. Either Morleys or Fitzgerald's pick them up, and then it costs a bit more—about \$2,000 or \$3,000—and then paying the costs for some family members who are in prison and flying them over with prison officers is another \$2,000.*¹⁵²⁷

Mrs Andrea Kyle-Sailor elaborated on the costs incurred by the community following a death on Palm Island:

I just want to you give you an example that we recently had and it brings in a lot of issues. We had someone tragically pass away here. He did not have a carer. He did not have insurance of any kind. The body had to be taken to Townsville for an autopsy, so the police recovered the body and took him to Townsville. It took them four months to bury him. All of the family members are

¹⁵²⁵ Public hearing transcript, Mount Isa, 31 May 2019, p 11.

¹⁵²⁶ Public hearing transcript, Cairns, 28 May 2019, p 8.

¹⁵²⁷ Public hearing transcript, Palm Island, 30 May 2019, p 11.

*on Centrelink, so \$50 a fortnight or \$100 a fortnight is a big whack out of their Centrelink to pay. When you are paying \$400 a fortnight for a \$6,000 or \$7,000 bill, it is going to take some time. It is about the logistics here. No doubt the funeral funds go around and try to get people in, but it is everyone's choice. Nobody thought he would go. He was not well, but he was relatively young. We do not know when people are going to go. In terms of getting his body back to Palm alone, the funeral directors would not release the body until the bill was paid, so he sat in Townsville. 'We want him here. We want him here. We want him here.' For four months they waited. That is just so you get an idea. This is something common. ... We do not have our funerals for at least two or maybe three weeks, whereas on the mainland they have it within a week.*¹⁵²⁸

Ms Shyla Mills told the committee of the importance of the Patient Transport Subsidy Scheme in this regards:

*When we went up to the cape and Torres recently—last year—we talked to people about some of the challenges and one thing that came up particularly in relation to this is the Patient Transport Subsidy Scheme which is currently under review. But something around that is the fact that they will send you and fund you to go to treatment often with a carer but if you die at treatment you are not automatically funded to go home. ... The body is not automatically brought back. To someone on Torres Strait, for example, that is extremely expensive. Within the plane they have to buy three seats to get the coffin back. It is extremely expensive and often go on a boat or a barge across to their own land. In Torres Strait they have worked out a little way that they can get them at least to Thursday Island but then you have to get them back to your island. There is a little bit of a compromise but it is one of the challenges and we are working with the Patient Transport Subsidy Scheme about that.*¹⁵²⁹

The challenges facing Indigenous communities during a family members' palliative care treatment, and then the hardships imposed following a death as outlined above are clear and apparent. Some suggestions and current programs to improve these times of crisis for Indigenous communities are outlined below. Specifically, building capacity to deliver culturally appropriate palliative care and advance care planning.

15.3.4.7 Building capacity to deliver culturally appropriate palliative care

Dr Brogan advised:

*... we need the right care at the right time in the right place but also delivered by the right people. If I look at Indigenous palliative care and places like Palm Island, there is a crying need—a really big need—for Indigenous health workers and carers to be available so that people can have the choice of being cared for at home and not just in the local hospitals, which are doing really good work in changing the way they are working. There is a need for training of their own to care for their own, like what is happening in Bamaga.*¹⁵³⁰

In this regard, PCQ recommended that palliative care services wishing to engage with the community should create partnerships with Aboriginal Medical Services, which usually are trusted by the community.¹⁵³¹

Professor Yvonne Cadet-James from the Apunipima Cape York Health Council stated that '[i]t is all about partnerships':

If you have health workers in the community who understand our people, working in partnership with someone who is committed to being open to understanding about the cultural aspects of

¹⁵²⁸ Public hearing transcript, Palm Island, 30 May 2019, p 12.

¹⁵²⁹ Private briefing transcript, Brisbane, 23 January 2019, p 20.

¹⁵³⁰ Public hearing transcript, Townsville, 29 May 2019, p 15.

¹⁵³¹ Submission 1891, p 55.

*providing care, then that works. That is complex and sometimes very difficult because I know that as a nurse we all come with our training that basically says that this is our discipline and this is the way that care is provided. Sometimes it is very difficult, unless you find someone who is open to be in that partnership, to provide that collaborative care with an understanding from both a western perspective and a cultural perspective. It does happen and when it does happen it works really well.*¹⁵³²

Dr Brogan also added:

*What we have been doing is education and training for staff to be able to do basic palliative care and recognise people's needs, but we are struggling with resources to do that. We see it as so important. We are also listening to what the local people want. You know what they tell us? They do not just want their clinicians to see them in the GPs' rooms or the hospitals, they want care to be delivered at home. Many of the elders here that I have talked to have said that they want to be able to do that at home, but there is not the community nursing service, there is not the outreach, there is not the supports for people to actually stay at home. Even on a place like Palm Island where you would think everyone would feel very comfortable coming to their local hospital, there are many people who will not come here and will not come until the last moment even or not come at all. There is a real need for more community services to go out to people where they are, not just specialists in-reaching into the local areas but the local services going out to the people as much as providing in-patient services as well.*¹⁵³³

15.3.4.8 Advance care planning in Indigenous communities

Throughout the inquiry, the committee heard of the importance of all Queenslanders being more aware of advance care plans and the benefits of having end-of-life plans in place before any loss of capacity. With Indigenous Queenslanders having higher rates of death and disease than non-Indigenous Queenslanders, these issues are of additional priority.

Mrs Kyle-Sailor spoke about the power of attorney:

*...with Murriss, we do not think about it until it is too far gone. We go, 'Oh, they're going simple. Oh, they are silly. The drugs are getting to them,' and all the rest of it. Realistically, we need to do a power of attorney when we are really young. ... People have come to our service for a power of attorney and I know from going through it with my mum that they lost capacity a long time ago, so it is too late.*¹⁵³⁴

Ms Debbie D'Urso, an advanced care planning facilitator at Townsville Hospital, also raised this as an issue in terms of making one's wishes known:

*The statement of choices has one with an Aboriginal and Islander approved cover which has a simpler explanation. I have been working with the Indigenous liaison officers at the hospital to try to get more discussions. One other thing I find is that people are dying before they get back on to country. One of the reasons for that is they have never talked about it openly. It is not written anywhere where someone can say, 'This person needs to go back now.' It is about the timing of getting them home. That is something I hear quite a bit, that the need to go back to country is not met.*¹⁵³⁵

¹⁵³² Public hearing transcript, Cairns, 28 May 2019, p 11.

¹⁵³³ Private briefing transcript, Brisbane, 23 January 2019, p 19.

¹⁵³⁴ Public hearing transcript, Palm Island, 30 May 2019, p 9.

¹⁵³⁵ Public hearing transcript, Townsville, 29 May 2019, p 6.

15.3.5 Access to palliative care for culturally and linguistically diverse people

Australia is one of the most culturally diverse countries in the world with an increasing ageing culturally and linguistically diverse (CALD) population.¹⁵³⁶ One in three people in Australia were born overseas with the majority of these people born in non-English speaking countries. Many of these overseas-born Australians face barriers to accessing quality support and services that contribute to good health care outcomes.¹⁵³⁷

The difficulty for palliative care service providers is that the older CALD population in Australia is not homogenous and therefore the needs of individuals vary greatly. Some of the barriers include a poorer socioeconomic status compared with the older Anglo-Australian population, language barriers to accessing services, and different cultural practices and norms that result in a lack of understanding about how to access and use services.¹⁵³⁸

Palliative Care Australia believes that culturally appropriate care is of particular relevance at the end of life and has called for health care providers to recognise that western medicine's approach to health care may be 'alien to patients from different cultural backgrounds'.¹⁵³⁹

In this regard, PCA calls for individualised care that takes into consideration a range of factors and other cultural matters to be considered when providing care, including:

- care setting - there may be strong resistance to institutionalised care
- language and communication - English language skills not universal
- role of the family in caring
- diet and food
- personal care rituals
- specific cultural beliefs and religious practices.¹⁵⁴⁰

Palliative Care Australia recommends initiatives to build cultural competencies to help 'health professionals understand each patient's view of their situation and their expectations of the mode of decision making and type of care that should follow'.¹⁵⁴¹ Palliative Care Australia states that while it is not realistic for health professionals to understand all cultural beliefs relating to illness, it is 'reasonable

¹⁵³⁶ Palliative Care Queensland, *Palliative Care and Culturally and Linguistically Diverse Communities – Position Statement*, p 3, <https://palliativecare.org.au/wp-content/uploads/2015/08/PCA-Culturally-and-Linguistically-Diverse-Communities-and-Palliative-Care-Position-Statement.pdf>.

¹⁵³⁷ Australian Government, Australian Institute of Health and Welfare, *Older Australia at a glance*, <https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/diversity/culturally-and-linguistically-diverse-people>.

¹⁵³⁸ Australian Government, Australian Institute of Health and Welfare, *Older Australia at a glance*, <https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/diversity/culturally-and-linguistically-diverse-people>.

¹⁵³⁹ Palliative Care Queensland, *Palliative Care and Culturally and Linguistically Diverse Communities – Position Statement*, p 2, <https://palliativecare.org.au/wp-content/uploads/2015/08/PCA-Culturally-and-Linguistically-Diverse-Communities-and-Palliative-Care-Position-Statement.pdf>.

¹⁵⁴⁰ Palliative Care Queensland, *Palliative Care and Culturally and Linguistically Diverse Communities – Position Statement*, p 3.

¹⁵⁴¹ Palliative Care Queensland, *Palliative Care and Culturally and Linguistically Diverse Communities – Position Statement*, p 3.

that they understand this in relation to populations they see often, and have the skill to identify when they need further assistance and the pathways to access this assistance'.¹⁵⁴²

Palliative Care Australia also recommends building capacity within CALD communities that could start with providing educational materials in community languages and seeking information from these communities to better inform the health system on culturally appropriate approaches to care.¹⁵⁴³

The committee heard direct evidence from service providers about demand and delivery of palliative care services for culturally and linguistically diverse communities.

This included representatives of the Ethnic Communities Council of Queensland (ECCQ). The ECCQ focuses on supporting and advocating for the needs and interests of between 30-40 CALD communities in Queensland, and includes a community home care service 'Diversicare', and a RACF 'Berlasco Court'.¹⁵⁴⁴

It was noted that Berlasco Court is one of the few culturally specific service providers of aged care in Queensland.

The ECCQ raised general concerns with funding and workforce needs to support CALD communities. In relation to staffing, Mr Peter Last, CEO of ECCQ, stated:

*I think the levels of education and understanding of workers compared to the risk of the service that they are required to provide is not necessarily understood, because the most vulnerable people require quite intuitive understanding about their requirements, yet with the workforce we are dealing with that is available for the money it is often incredibly difficult to match those needs. I think it is about people management and staffing.*¹⁵⁴⁵

The ECCQ also outlined the difficulties in the interface between hospitals and RACFs and the community, noting the communication processes between these different providers can cause additional challenges for CALD communities.¹⁵⁴⁶

The ECCQ highlighted other challenges of CALD communities, noting 'Different cultures have unique practices or rituals in dying, and these should be supported as much as structure and policy allow'.¹⁵⁴⁷ Mr Last further explained:

*This may include managing what I call the dignity of risk—that is, respecting traditional culture practices despite perhaps a medical risk. For example, the consumption of certain food or drink may be culturally appropriate, however it may have a medical risk, for example of aspiration. A person may also desire to be close to earth, despite the risk that it may be an infection risk, for example.*¹⁵⁴⁸

Mr Last summarised the complex and sensitive nature of delivery of end-of-life and palliative care services:

¹⁵⁴² Palliative Care Queensland, *Palliative Care and Culturally and Linguistically Diverse Communities – Position Statement*, p 3.

¹⁵⁴³ Palliative Care Queensland, *Palliative Care and Culturally and Linguistically Diverse Communities – Position Statement*, p 4.

¹⁵⁴⁴ Mr Peter Last, Chief Executive Officer, Ethnic Communities Council of Queensland, public hearing transcript, Brisbane, 18 October 2019, p 2.

¹⁵⁴⁵ Public hearing transcript, Brisbane, 18 October 2019, p 6.

¹⁵⁴⁶ Public hearing transcript, Brisbane, 18 October 2019, p 3.

¹⁵⁴⁷ Mr Peter Last, Chief Executive Officer, Ethnic Communities Council of Queensland, public hearing transcript, Brisbane, 18 October 2019, p 3.

¹⁵⁴⁸ Public hearing transcript, Brisbane, 18 October 2019, p 3.

In summary, palliative care and end-of-life care decision-making is sensitive and complex for all members of the community but even more challenging for the CALD people. All providers should heavily involve a person's family. Advice should be sought from elders, leaders and religious personalities to truly accommodate a person's wishes.

The committee also heard from Mr Choe Kam Tan, Founder and Managing Director of Jeta Gardens, Bethania. Jeta Gardens provides aged care, end-of-life and palliative care services which are tailored to the ageing Chinese and ethnic population.¹⁵⁴⁹

Mr Tan noted the increasing demand for end-of-life and palliative care, and particular challenges for the Chinese and ethnic community.¹⁵⁵⁰ These included the cultural practice that generally people should not talk about end of life and dying. Mr Tan told the committee:

*For Asians, there are a few things that are of particular interest. It is terrible even to talk to them about end of life and dying. They do not want to talk about it. Neither do the children. It makes it very difficult. Any delay in managing people's end of life—we have to do it early so that they can have better quality of life, a dignified life. A lot of Asians try not to talk about it. We have to put extra effort in, to convince them and use different language to be able to talk to them and communicate with them and the family, to be able to deliver a service.*¹⁵⁵¹

Mr Tan outlined some of the innovative and practical measures being undertaken by Jeta Gardens to make residents feel supported and connected to their culture and communities. These included having:

- different types of meals available to residents (serving Western, Asian and vegetarian food)
- a prayer room for those of Muslim faith
- a special heat detector to allow incense to be used in a room without setting off the smoke detector.

Mr Tan also provided the following example of how Jeta Gardens caters to its Buddhist residents:

*I just want to mention what we can do for Buddhists, for example. When a Mahayana Buddhist passes away, they would expect that the body should not be touched for eight hours. In today's operation, anyone who passes away in an aged-care home will be peacefully taken away within an hour, but that is showing total disrespect to someone's belief. We understand that. We realise that, so we have designed it so that when someone passes away in a bed, using a bed with wheels—without touching them—they can be pushed through the door—and the door is bigger than the bed width—to the lift—the lift is bigger than the three dimensions of the bed—down to the ground floor if it is multistorey to a quiet room where, if they wish to do a service, a special room is designed for them before they are taken to the mortuary.*¹⁵⁵²

15.3.6 Access to palliative care for members of the LGBTIQ+ community

Research from Carers Queensland in early 2017 'highlights that despite significant social changes in Australia, people in the lesbian, gay, bisexual, transgender, intersex and queer communities still fear connecting with, or have had negative experiences of, health and social care providers'.¹⁵⁵³ The former

¹⁵⁴⁹ Public hearing transcript, Brisbane, 18 October 2019, p 4.

¹⁵⁵⁰ Public hearing transcript, Brisbane, 18 October 2019, p 5.

¹⁵⁵¹ Public hearing transcript, Brisbane, 18 October 2019, p 5.

¹⁵⁵² Public hearing transcript, Brisbane, 18 October 2019, p 5.

¹⁵⁵³ Joint submission from Palliative Care Queensland, Health Consumers Queensland, Council on The Ageing Queensland, and Carers Queensland, submission 1892, p 10; Carers Queensland, 'Improving access to aged residential respite care', February 2017, <http://www.carersaustralia.com.au/storage/residential-respite-care-report.pdf>.

Health and Community Services Committee also noted in its report that '[f]or lesbian and gay patients who lose decision-making capacity near the end of life, health providers and the patient's partner may not be aware that the appropriate substitute decision maker does not have to be a relative'.¹⁵⁵⁴

The AASW emphasised the importance of holistic needs of a person, including their emotional, social and psychological wellbeing. It submitted that there was a lack of holistic and psychosocial approaches to palliative care and end-of-life care particularly for vulnerable populations, such as those experiencing homelessness, CALD communities and people identifying as lesbian, gay, bisexual, transgender, intersex and queer.¹⁵⁵⁵ The AASW recommended more targeted approaches to palliative and end-of-life care for vulnerable populations to address this issue.¹⁵⁵⁶ QNMU supported the view that person-centred care should be at the core of palliative care and that as part of delivering person-centred care at end-of-life, '[s]pirituality and sexuality must also be essential elements' of this approach to care.¹⁵⁵⁷

Committee comment

Delivery and access

End of life and palliative care services provide high level pain relief and other clinical support as well as counselling for those who have been diagnosed with a life limiting illnesses or who are actively dying. These services also extend to counselling support for the family and friends caring for a dying loved one.

Access to quality palliative care and end-of-life care is as important as health care at any other stage of life, yet for many it is not readily available. There is a strong expectation that all Queenslanders and all communities can access services 24 hours a day seven days a week, if and when they need to. Sadly, access to services at a local level is often problematic, particularly for Queenslanders in regional, rural and remote communities. Because of Queensland's system of regional hospital and health services which determine how funding allocated by the government is spent, the delivery of palliative care and end-of-life care services varies across the state, particularly after normal office hours. As Queensland's population continues to increase and people live longer, the need for palliative and end-of-life care will only increase.

Where they are available, privately operated hospices provide end-of-life care to complement the services provided by the hospitals, but there are no hospices located outside of South East Queensland. The committee encourages Primary Health Networks, Hospital and Health Services and community organisations to collaborate on other ways to deliver palliative care services particularly in relation to community hospices in regional, rural and remote Queensland.

Strategic planning for the delivery of palliative care services at the national level acknowledge the need to improve the delivery of services, but lacks action-level plans to implement the improvements that are needed. The Australian Government should finalise and release its implementation plan and the monitoring and evaluation plan for the *National Palliative Care Strategy 2018* as a priority. The Queensland Government should update its *Statewide Strategy for End-of-Life Care 2015* to provide clear targets and standards for access to and the delivery of palliative care and end-of-life care services across Queensland, including to Aboriginal and Torres Strait Islander communities, CALD communities, LGBTIQ+ communities and people living in regional, rural and remote areas. The strategy should also include specific reporting obligations for hospital and health services responsible for the delivery of

¹⁵⁵⁴ Queensland Parliament, Health and Community Services Committee, Report no. 22, *Palliative and community care in Queensland: towards person-centred care*, p 47.

¹⁵⁵⁵ Submission 1288, p 5.

¹⁵⁵⁶ Submission 1288, p 20.

¹⁵⁵⁷ Queensland Nurses and Midwives' Union, submission 1213, p 31.

palliative and end-of-life care services to report their performance against the targets and standards to be included in the strategy.

All Queenslanders should have the right to a 'good death' with the support of palliative care and end-of-life care services.

Recommendation 43 National strategy implementation plan and monitoring and evaluation plan

The committee recommends that the Australian Government finalise and publish the Implementation Plan and the Monitoring and Evaluation Plan for the *National Palliative Care Strategy 2018* as soon as possible.

Recommendation 44 Revision of the 2015 End-of Life-Strategy

The committee recommends that the Queensland Government revise and update the *Statewide Strategy for End-of-Life Care 2015* in conjunction with the Australian Government, Primary Health Networks, Palliative Care Queensland and other peak bodies, consistent with the Clinical Services Capability Framework, to:

- specify what palliative care services and end-of-life care services are to be provided and in what form by government and non-government providers, including: specialist care services, telephone support, access to pharmacy services, grief and bereavement support, the delivery of awareness programs for health professionals and the general public, and interactions with aged care
- provide clear, meaningful targets for accessibility to, and the delivery and timeliness of, palliative care and end-of-life care services to all Queenslanders regardless of their location, including communities with special cultural and other needs, who are located in regional, rural and remote areas
- require that Queensland Health is responsible for coordinating and implementing the strategy across all Hospital and Health Services, and that department report annually on the performance by all Hospital and Health Services against the accessibility, delivery and timeliness targets for palliative care and end-of-life care services
- provide goals and actions related to the delivery of training and education for palliative care and end-of-life workers
- link to other strategies and plans for the recruitment and retention of staff, and
- acknowledge that a key principle of palliative and end-of-life care is person-centred care.

Committee comment

Person-centred care

Reflecting on the current palliative care model in Queensland, a number of stakeholders consistently raised the need for person-centred care, despite the complexity in delivering holistic care that acknowledges the medical, psychological, physical and cognitive needs of patients.

Submissions to the inquiry raised the importance of person-centred care in its ability to recognise a patient's own life story, culture, interests and beliefs through the provision of individualised care that meets their unique needs. The committee also heard that person-centred care should recognise the important role of a patient's significant others.

To improve the quality of palliative care in Queensland, stakeholders advocated for a person-centred model; however, it was noted that funding is the main obstacle in ensuring the delivery of a person-centred palliative care.

The committee recommends that any changes to the delivery of and access to palliative care services in Queensland promote and uphold the principles and values of person-centred care.

Recommendation 45 Person-centred care

The committee recommends that any changes to the delivery of and access to palliative care services in Queensland promote person-centred care.

Committee comment

Coordination of care in a fragmented system of delivery

The committee notes the importance of a coordinated approach to palliative care in Queensland.

Evidence provided by stakeholders suggests the current system is fragmented and interface of services is complex and disjointed.

Although there are both state-wide and national strategies for end-of-life care and palliative care, evidence suggests these are not effective in ensuring an integrated and coordinated approach to palliative care in Queensland.

Concerns were raised that the Queensland End-of-Life Strategy is not being implemented appropriately, with a lack of consistency and piecemeal approach being undertaken by individual Hospital and Health Services.

Suggestions were made that the department should take oversight and responsibility for implementation and provide more specific guidelines and targets to achieve the plans aims.

The positive impact of nurse practitioners was highlighted by stakeholders, and it was suggested that they should be further utilised to maximise their role in the coordination of care.

Performance Reporting

The committee notes the call for increased transparency and accountability of palliative care services in Queensland.

There is limited data available to assist in determining need for palliative care services, as well as outcomes being achieved by these services.

The committee commends the work of the Palliative Care Outcomes Collaboration (PCOC) to consolidate available data and to measure and benchmark patient outcomes in palliative care, however notes the data is limited by those services which agree to contribute data and reporting is not mandatory.

The committee recognises the need to obtain more data to allow for accuracy in predicting service demand and quality of services.

Recommendation 46 Increased transparency and accountability for palliative care services

The committee recommends that the Queensland Government increase transparency and accountability of palliative care services, by mandating reporting of data and setting clear performance standards.

Committee comment

Palliative care in residential aged care facilities

Difficulties accessing good palliative care and end-of-life care also affect people who have made their homes in residential aged care facilities. The committee heard that the funding provided by the Australian Government to enable facility operators and general practitioners to provide palliative and end-of-life care in these facilities is insufficient to provide the clinical care dying residents require.

Specialist palliative services should be integrated into residential aged care facilities or have close connections and be able to provide the necessary services and supports to residential aged care facilities.

Palliative care at home

Action needs to be taken to allow more people who want to remain at home, to be supported.

Communities need to be further resourced to be able to provide services and assistance to meet the needs of palliative care patients. This includes exploring ways to provide palliative care in aged care packages.

Recommendation 47 Assistance for people wishing to die at home

The committee recommends that the Queensland Government and Primary Health Networks explore ways to fund and provide further assistance to communities and families to enable people to die at home supported by end-of-life care through: expansion of community and in-home nursing services; expansion of community care programs; supporting community-based medical aids and equipment loan schemes; and increased resources for the Hospital in the Home program which provides high-level care in the home when patients require it.

Committee comment

Hospice models of care

Positive accounts were provided to the committee about hospice models of palliative care. The committee notes the dedicated work undertaken by many community volunteers and paid workers to provide palliative care support in a range of settings. The committee notes there are several community based funded hospices in South East Queensland.

There are established palliative care facilities operated by Hospital and Health Services, such as the Gordonvale 12 bed facility and the Caloundra Hospital Dove Cottage facility the committee visited during its inquiry.

Despite this, the committee heard there are a limited number of hospices in regional, rural and remote Queensland.

See section 3.13 for a discussion on paediatric palliative care services in Queensland.

Recommendation 48 Assistance for regional hospices

The committee recommends that the Queensland Government with assistance from Primary Health Networks examine ways to help establish viable hospices outside of South East Queensland.

Recommendation 49 Paediatric palliative care

The committee recommends that all levels of government explore opportunities to establish a paediatric palliative care hospice outside of South East Queensland.

Committee comment

Providing after-hours palliative care services

The committee acknowledges the inadequate access to after-hours palliative care services particularly in regional Queensland. In some instances, lack of access to after-hours palliative care, leads to distress for palliative care patients. The committee agrees that after-hours palliative care should be available to all Queenslanders suffering from a life-limiting illness

Recommendation 50 After hours palliative care

The committee recommends that the Queensland Government explore options to improve after-hours access to palliative care services, to ensure all Queensland palliative care patients have access to after-hours palliative care regardless of whether they are at home or in a residential aged care facility, hospice or hospital.

Committee comment

Regional, rural and remote communities

The committee was encouraged by the announcement of Hon Dr Steven Miles, Minister for Health and Minister for Ambulance Services, that the Queensland Government had provided an additional \$17 million in the 2019-20 State Budget for 2019-20 and 2020-21 'for initiatives in rural and remote areas to support the delivery of palliative care to people in community-based settings'.¹⁵⁵⁸

The committee considers the enhancement of telehealth services, with funding for digitally delivered clinical services and the delivery of better patient information systems, as immediate way to address the lack of specialist palliative services available to communities in regional rural and remote areas of Queensland.

The committee heard of circumstances in which there was a lack of ability to contact palliative care staff after-hours. This led to other services, such as the Queensland Ambulance Service, to be called whereby the patient would be transferred to a public health facility. This creates a further burden on the public health system in Queensland.

Recommendation 51 Centralised 24/7 telehealth service

The committee recommends that priority funding be allocated to establish a centralised 24-hour, seven day telehealth service available to practitioners caring directly for palliative patients throughout Queensland, and to develop a statewide supportive information system to allow practitioners to access real-time patient information for rapid response and appropriate treatment recommendations.

Recommendation 52 Capacity building for telehealth services

The committee recommends further development and capacity building of telehealth or other digital services for patient consultations to enable people in regional, rural and remote areas to access health services not locally available.

Committee Comment

Paediatric palliative care

The committee notes the important specialised services provided by paediatric palliative care providers, and the increasing demand for these services.

The committee visited Hummingbird House and highly commends the dedicated work of its staff and volunteers and indeed all who perform paediatric services in Queensland, including the Paediatric Palliative Care Service.

Culturally and linguistically diverse communities and other vulnerable cohorts

The committee notes the additional challenges faced by culturally and linguistically diverse communities in accessing palliative care.

Palliative and end-of-life care needs to be equally available and accessible to all persons, regardless of their culture or other differences.

There is a need for further training and education of staff and facilities to understand and best meet the needs of persons in culturally and linguistically diverse communities.

The committee notes the innovative models and initiative being undertaken by groups such as Jeta Gardens and encourages other service providers to increase their cultural awareness and provision of culturally appropriate services.

¹⁵⁵⁸ Minister for Health and Minister for Ambulance Services, Honourable Dr Steven Miles, Media Statement, 25 July 2019, <http://statements.qld.gov.au/Statement/2019/7/25/new-wish-ambulance-grants-dying-wishes>.

15.4 Spiritual and pastoral care

A number of submitters and witnesses to the inquiry highlighted the importance of spiritual care as a component of the provision of palliative care.¹⁵⁵⁹

It was noted that the WHO definition of palliative care includes ‘an emphasis on spiritual care’.¹⁵⁶⁰ The Most Reverend Dr Phillip Aspinall of the Anglican Church told the committee:

*Spiritual care or, as it is sometimes called, pastoral care provides a supportive, passionate presence with people at times of significant transitions, illness, grief or loss. It is an integral part of holistic care inextricably linked with quality of life.*¹⁵⁶¹

The Uniting Church in Australia Queensland Synod noted ‘spiritual and pastoral care is fundamental to the delivery of high quality person centred care’.¹⁵⁶² It further explained the important role of spiritual care at end of life:

*Whether a person affiliates with a religious tradition or not, they have spiritual care needs. We believe an approach that incorporates spiritual care holistically into our teams and services will deliver the best outcomes for the people and communities we work with. We define spiritual care as responding to the fundamental human need for meaning, purpose and deep relationships. These relationships include those with other people, self, those with creation, with the sacred or God. Spiritual care is offered to every person regardless of beliefs. It may include faith-specific support, exploring questions of meaning and purpose, enhancing relationships, reconciliation and healing, finding meaning and purpose in life stories, rites, rituals, mindfulness, meditation or prayer to enable people to experience life in all its fullness. Research increasingly demonstrates the importance of spiritual and pastoral care in health and aged care settings. This type of care plays a role in reducing distress and enhancing a person’s ability to cope with illness and positively respond to changing life circumstances. Care that values spiritual elements such as faith, hope, meaning making, compassion and connections has been shown to promote health and quality of life.*¹⁵⁶³

Similarly, Churches of Christ in Queensland submitted:

*...we view spiritual care as being as important as physical care, and even more so at the end of life. Working as a team our nurses and chaplains along with family members are able to be attentive and listen to people as they near the end of life, offering them comfort and compassion. By doing this, we foster a sense of openness and spiritual wellbeing for those in our care, which is part of offering people dignity at the end of life.*¹⁵⁶⁴

The ACSQ agreed that ‘people should be supported holistically on the inevitable journey to death – including their spiritual needs’. The ASCQ raised concern, however, with ‘significant gaps in understanding and education about spirituality and spiritual care in palliative care settings across the Queensland community, including among aged care staff and health providers’.¹⁵⁶⁵ It suggested this issue could be addressed by increasing the number of skilled and trained staff ‘reflecting a view of

¹⁵⁵⁹ See, for example, Ms Shyla Mills, Chief Executive Officer, PCQ, private hearing transcript, Brisbane, 23 January, p 23; submissions 1229, 1268, 1281.

¹⁵⁶⁰ Most Reverend Dr Phillip Aspinall, Anglican Church, public hearing transcript, Brisbane, 23 August 2019, p 16.

¹⁵⁶¹ Public hearing transcript, Brisbane, 23 August 2019, p 16.

¹⁵⁶² Submission 1268, p 34.

¹⁵⁶³ Submission 1268, p 34.

¹⁵⁶⁴ Submission 1281, p 10.

¹⁵⁶⁵ Submission 1229, p 7.

palliative care as holistic, integrating physical, social, psychological, spiritual and cultural aspects of care'.¹⁵⁶⁶

Stakeholders called for additional funding to support the provision of spiritual and pastoral care.¹⁵⁶⁷

The Most Reverend Dr Phillip Aspinall of the Anglican Church noted:

*Queensland Health also acknowledges the importance of this spiritual dimension of care, especially at the end of life, but Queensland Health does not fund this dimension of care. It relies entirely on churches and religious bodies to provide this care in public hospitals by properly qualified professionals without any financial contribution at all by Queensland Health. I submit that this committee should recommend to the Queensland government that it contribute to providing spiritual care as an indispensable dimension of palliative care, as do other Australian states.*¹⁵⁶⁸

Reverend Linda McWilliam, Anglicare Southern Queensland suggested:

*We would find it really helpful in community settings if we had some funding for that spiritual care component, because we seek to qualify them and train them professionally in all areas of palliative care, dementia and community care services. We really feel strongly that those spiritual practitioners can do some really good work in those circumstances.*¹⁵⁶⁹

Mr Michael Hart, Chief Mission and Identity, Southern Cross Care agreed:

*I take on board the idea of the provision of resources and funding around that. Whilst we do it because we believe it is integral to our faith tradition, it has a broader worth as well. That is something to be considered.*¹⁵⁷⁰

Committee Comment

The committee acknowledges the important role of spiritual and pastoral care at end of life. The committee notes the calls for additional resourcing to ensure these services continue to be delivered.

Stakeholders highlighted the significance of supporting not only a person physically, but spiritually in the delivery of high quality, person-centred palliative care. Incorporating an individual's spiritual and pastoral care needs supports a holistic approach that integrates physical, social, psychological and cultural aspects in the provision of palliative care. Witnesses to the inquiry acknowledged the importance of providing this dimension of care in all settings.

¹⁵⁶⁶ Submission 1229, p 7.

¹⁵⁶⁷ See, for example, Reverend Linda McWilliam, Anglicare Southern Queensland, public hearing transcript, Brisbane, 4 July 2019, p 71; Mr Michael Hart, Chief Mission and Identity, Southern Cross Care, public hearing transcript, Brisbane, 4 July 2019, p 71; Ms Glenys Webby, Director, Industry Service Reform & Innovation, UnitingCare Queensland, Uniting Church in Australia Queensland, p 71.

¹⁵⁶⁸ Public hearing transcript, Brisbane, 23 August 2019, p 16.

¹⁵⁶⁹ Public hearing transcript, Brisbane, 4 July 2019, p 71.

¹⁵⁷⁰ Public hearing transcript, Brisbane, 4 July 2019, p 71.

16 Funding for end-of-life care and palliative care

16.1 What is happening?

As outlined in Chapter 1, both the Australian Government and state/territory governments are responsible for funding palliative care services under the National Health Reform Agreement.

The Australian Government has full funding and program responsibility for aged care and has lead responsibility for general practitioner (GP) care and primary health care. The Australian Government is also responsible for the provision of palliative care services in the community by GPs and in residential aged care facilities.¹⁵⁷¹ The Australian Government does not directly fund palliative and hospice care services but provides financial assistance to the Queensland Government to operate these services as part of their health and community service provision responsibilities.¹⁵⁷²

The Australian Government provides funding for palliative care services through Medicare Benefits Schedule (MBS) rebates for specialist medical services such as attendances in hospitals or in the patients' homes and palliative medicine case conferences, and via the Pharmaceutical Benefits Schedule (PBS) for palliative care related prescriptions. Funding is also allocated via the sub-acute care component of hospitals' Activity Based Funding (ABF), which covers palliative care as well as rehabilitation care, geriatric evaluation and management care, and psychogeriatric care.¹⁵⁷³

In Queensland, the Queensland Government is the system manager of the public health system, and has responsibility for the provision of palliative care services, with funding support from the Australian Government. This includes the provision of specialist palliative care services in the hospital and in the community. Queensland Health funds HHSs and NGOs to provide palliative care services in a range of settings, including in hospital, hospice, community, residential aged care and home settings.¹⁵⁷⁴

In 2017-18, the total amount spent across HHSs for palliative care services, including admitted patient allocation, non-admitted patients and community palliative care services to admitted patients, was approximately \$101,046 million.¹⁵⁷⁵

Table 1 below sets out annual expenditure across Queensland Hospital and Health Services (HHSs) for palliative care services from 2013-14 to 2017-18.

2013-14	2014-15	2015-16	2016-17	2017-18
\$99,362	\$98,756	\$101,352	\$103,696	\$101,046

Source: Queensland Health, correspondence dated 23 January 2019, *Briefing on aged care, palliative care and legal documents relevant to end-of life care in Queensland*, p 23.

¹⁵⁷¹ Queensland Health, *Queensland Health Palliative Care Services Review: Initial Outcomes*, March 2019, p 2, https://www.health.qld.gov.au/__data/assets/pdf_file/0037/848359/palliative-care-services-review.pdf

¹⁵⁷² Community Affairs References Committee, *Palliative Care in Australia*, October 2012, p

¹⁵⁷³ Lemmon, E, Woods, MC & Van Gool, K, Centre for Health Economics Research and Evaluation (CHERE), University of Technology Sydney, *Palliative care in residential aged care: Identifying and funding palliative care needs in Australia*, 2018.
Sydney: University of Sydney.

¹⁵⁷⁴ Queensland Health, *Queensland Health Palliative Care Services Review: Initial Outcomes*, March 2019, p 2; Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 21.

¹⁵⁷⁵ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 21.

Queensland Health estimated that in the last financial year, 2018-19, HHSs spent approximately \$114 million on palliative care services.¹⁵⁷⁶

The 2019-20 state budget saw an announcement of an additional \$17 million for community-based palliative care services, with a focus on rural and remote areas of Queensland.¹⁵⁷⁷ In October 2019, the state government also announced a commitment of \$8.25 million over five years for the Hummingbird House children's hospice in Brisbane.¹⁵⁷⁸

The healthcare purchasing negotiations mentioned in Chapter 15 result in 16 HHS annual service agreements. These agreements outline the services that Queensland Health will purchase from each HHS and how much will be paid for the provision of these services, in what is described as activity-based funding.¹⁵⁷⁹ Activity-based funding (ABF) is a funding method for public hospital services based on the number of weighted services provided to patients, and the price to be paid for delivering those services.¹⁵⁸⁰

Public palliative care services are currently funded by the sub-acute care components of ABF for public hospitals, with sub-acute care being a collective term which covers not only palliative care, but also rehabilitation, geriatric evaluation and psychogeriatric care. The agreements made by Queensland Health mean that each HHS has a different model for funding and levels of care and service delivery to allow each HHS to respond to its local needs, given the existing infrastructure and arrangements that it has in place.¹⁵⁸¹ That is, each HHS determines how it distributes the ABF to each of the sub-acute specialised care types. There are no specific activity outcomes or measurements tied to this funding.

Queensland Health also provides funding to 11 non-government organisations which are contracted to deliver palliative care services. In 2018-19, Queensland Health provided \$9.2 million to NGOs to deliver palliative care services.

Most of this funding is used by these NGOs to provide clinical community-based palliative care services. However, some funding is used for education and information services such as the PalAssist online and telephone service.¹⁵⁸²

Queensland Health advised that it will provide an additional \$10 million over 4 financial years from 2019-20 to 2022-23 for the seven existing non-government palliative care services/hospices.¹⁵⁸³

According to PCQ, these non-government hospice services operate in a primary care model, with medical services largely funded through MBS and PBS sources.¹⁵⁸⁴

¹⁵⁷⁶ Professor Keith McNeil, Acting Deputy Director-General, Clinical Excellence Division, Queensland Health, public hearing transcript, Brisbane, 18 October 2019, p 12.

¹⁵⁷⁷ Queensland Government, Queensland Budget 2019-20 – Service Delivery Statements Queensland Health, p 6, <https://budget.qld.gov.au/files/2019-20%20QH%20SDS.pdf>.

¹⁵⁷⁸ The Honourable Steven Miles, Minister for Health and Minister for Ambulance Services, 'Hummingbird House receives big funding boost from Qld Government', media release, 11 October 2019, <http://statements.qld.gov.au/Statement/2019/10/11/hummingbird-house-receives-big-funding-boost-from-qld-government>.

¹⁵⁷⁹ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 21.

¹⁵⁸⁰ Administrator National Health Funding Pool, Activity-Based Funding, <https://www.publichospitalfunding.gov.au/public-hospital-funding/funding-types>.

¹⁵⁸¹ Ms Kathleen Forrester, private hearing transcript, Brisbane, 6 February 2019, p 16; Submission no. 1891, Palliative Care Queensland, p 15.

¹⁵⁸² Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 21.

¹⁵⁸³ Palliative Care Queensland, media release, 21 June 2019, 'Palliative Care Qld welcomes state budget boost to help more people receive care in their community', https://palliativecareqld.org.au/wp-content/uploads/2019/06/PressRelease_PallCare-in-State-Budget.pdf.

¹⁵⁸⁴ Submission 1891, p 16.

Non-government organisations (NGOs) also seek income or revenue from sources other than Queensland Health's funding, with the sources varying depending on the organisation and their business model. Palliative Care Queensland advised that some NGOs 'receive small proportions of their revenue as payments for scripted services under panel arrangements from HHSs directly to deliver palliative care services in the local area'.¹⁵⁸⁵

NGOs may also receive revenue/income from other sources including:

- donations and bequests
- fundraising activities/special event income
- private health insurance services
- other revenue from provision of services, and
- grants – from a range of sources including the Australian Government, other government and non-government sources.¹⁵⁸⁶

16.2 Issues

For many inquiry stakeholders, the issue of funding was a key area of concern. Some called for increases in funding while others identified issues with the current funding models, suggesting they had a detrimental impact on delivery of palliative care services in Queensland. Stakeholders suggested that changes to funding models are needed at both the state and federal level. Key issues raised by stakeholders are discussed below.

16.2.1 Amount of funding

The issue of whether adequate funding has been allocated to palliative care services in Queensland is inextricably linked to many of the issues canvassed within this report, particularly in relation to equitable access and workforce. Increases in funding were called for to allow for an increase in the provision of services, workforce and training development, education and public awareness, resourcing, infrastructure and coordination of services. This section considers funding in a broad sense.

Inquiry participants frequently stated that existing funding levels were inadequate and expressed the view that further investment in Queensland's palliative care services is required, particularly given the ageing population and future demands for palliative care.¹⁵⁸⁷

By way of example, Ms Suzanne Greenwood, Chief Executive Officer of Catholic Health Australia (CHA), advised the committee that CHA's report on palliative care described a number of barriers to providing good palliative care, the most significant of which included inadequate funding and restrictive funding models.¹⁵⁸⁸

Ms Carol Hope, State Council Member of PCQ, advised that the first of five priorities identified by PCQ 'is to increase funding. The demand for palliative care is increasing and the funding is not keeping up with that demand'.¹⁵⁸⁹ The Australian and New Zealand Society of Palliative Medicine similarly

¹⁵⁸⁵ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 22.

¹⁵⁸⁶ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 22, https://www.health.qld.gov.au/__data/assets/pdf_file/0025/852622/palliative-care-services-review-key-findings.pdf.

¹⁵⁸⁷ See, for example, submissions E130, E549, 444, 1108, 1229, 1223, 1233, 1234, 1243, 1245, 1249, 1252, 1254, 1263, 1282, 2388, 1301, 1360, 1400; Mr Compton, Public briefing transcript, Brisbane, 13 September 2019, p 64.

¹⁵⁸⁸ Public hearing transcript, Brisbane, 4 July 2019, p 67.

¹⁵⁸⁹ Public hearing transcript, Brisbane, 4 July 2019, p 81.

submitted that palliative care resourcing in Queensland must be responsive to the growing population and health demographic.¹⁵⁹⁰

Several key stakeholders were of the view that the Queensland Government needed to do more to ensure sufficient funding for a person-centred model of palliative care.¹⁵⁹¹ The Australian Family Association submission recommended '[t]hat funding for palliative care in Queensland be boosted substantially and services significantly expanded so that all terminally ill patients can receive the end of life care to which they are entitled as a fundamental human right'.¹⁵⁹²

In regard to delivering person-centred care, Dr Greg Parker of the QSPCSMDG advised:

*It has to be person-centric rather than system-centric. We struggle with that. To achieve this, however, needs more than goodwill; it needs meaningful investment of dollars that is not a patchwork approach. We see too much of that in our practice. I think universal access and delivery of best possible palliative care, independent of prejudices, the postcodes we live in, the time of day or where the person may be in their terminal disease trajectory, requires a concerted effort from government, the healthcare system and the community to really improve the current landscape. We cannot leave this to chance any longer.*¹⁵⁹³

In terms of palliative care provision in RACFs, Aged and Community Services Australia (ACSA), the aged care peak body supporting church, charitable and community-based, not-for-profit organisations, advised the committee:

*Providers are not adequately funded to respond to be all things to all older people requiring palliative care and due to the increasing demand for these services, struggle to meet the ever-increasing demand in a timely manner.*¹⁵⁹⁴

As referred to earlier, inadequate funding was identified as a key cause of a lack of palliative care services in rural and remote areas. The QNMU stated that funding of services was the key concern regarding the differences in delivering services across remote, rural, regional and metropolitan areas.¹⁵⁹⁵ Palliative Care Queensland also expressed the view that funding did 'not seem equitable throughout the regional, remote and rural areas compared to the metropolitan services' and argued that funding should follow the population's needs to be equitable'.¹⁵⁹⁶

The Uniting Church in Australia Queensland Synod referred to the need for increased funding to better deliver community-based palliative care, advising the committee that:

*Our inpatient palliative care services are only just able to meet patient demand at this time. Our hospitals do not provide direct community palliative care. This is done by referral to Queensland Health services or private providers such as Blue Care. Finding appropriate community care for our patients in the greater Brisbane area is difficult due to the level of funding received by community services, which limits their care offerings.*¹⁵⁹⁷

16.2.2 Funding model

A number of stakeholders raised issues with the funding models used by both the state and federal governments to allocate funds for palliative care services, as well as the impact that different sources

¹⁵⁹⁰ Submission 1252, p 6.

¹⁵⁹¹ PCQ, submission 1891; The University of Queensland, submission 1219; AMA, submission 1233, p 5.

¹⁵⁹² The Australian Family Association, submission 1310, p 1.

¹⁵⁹³ Public hearing transcript, Brisbane, 5 April 2019, p 4.

¹⁵⁹⁴ Submission 1285, p 4.

¹⁵⁹⁵ Submission 1213, p 28.

¹⁵⁹⁶ Submission 1891, p 54.

¹⁵⁹⁷ Submission 1268, p 21.

of funding across different jurisdictions can have on service provision. These issues are discussed in the sections below.

Some stakeholders also commented on funding models and their impacts more broadly. Palliative Care Queensland referred to research which shows that funding models influence provision and development of palliative care services.¹⁵⁹⁸ This view is borne out by the Queensland Specialist Palliative Care Services Medical Directors' Group's statement that equitable access to needs-based palliative care is difficult in Queensland due to 'poor service resourcing and infrastructure dictated by obsolete and disparate funding models'.¹⁵⁹⁹

Similarly, Dr Stephen Duckett, Health Program Director at the Grattan Institute, stated that palliative care services needed reform 'because the funding design and espoused policy objectives are not in alignment'.¹⁶⁰⁰

Mr Toby Hall, Group Chief Executive Officer of St Vincent's Health Australia, commented on the impact of different sources of funding using his experience in the provision of palliative care in RACFs. He made the following comment when the committee asked him about the transition from aged care to palliative care:

I absolutely believe that this is a funding issue. It is dealing with the bureaucracy between the different levels of government to allow access to funding to deliver palliation in aged-care facilities.

...

*With the right training and the support programs...we should absolutely be able to provide palliation within the aged-care facility. We just need to have the funding models and the bureaucracy broken through.*¹⁶⁰¹

16.2.2.1 State allocation of funding

Stakeholders raised issues with the packaging of palliative care funding with other sub-acute services, and the role HHSs play in determining the allocation of those funds amongst competing sub-acute services. One of the key issues raised was the lack of a statewide palliative care strategy to guide how HHSs allocate that funding and determine their activities, impacting on equitable access to good quality palliative care.

Ms Carol Hope told the committee:

*At the moment the situation is that there is no overarching expectation, policy or KPIs that everybody has to meet. What that then translates to is that it really does depend on where you live, what your diagnosis is and how old you are as to what services you can access and, more to the point, how you can get funding to access those services.*¹⁶⁰²

In its submission, PCQ advised that the current state funding model means that 'funding does not always filter down to on the ground community based palliative care services. Instead, funding goes into subacute services such as rehabilitation'. Palliative Care Queensland contended that 'this disadvantages people with life limiting illnesses who are not able to receive services because of such funding decisions'.¹⁶⁰³ Palliative Care Queensland also submitted that the inclusion of the funding

¹⁵⁹⁸ Submission 1891, p 16.

¹⁵⁹⁹ Queensland Specialist Palliative Care Services Medical Directors' Group, submission 2681, p 1.

¹⁶⁰⁰ Public briefing transcript, Brisbane, 23 August 2019, p 60.

¹⁶⁰¹ Public hearing transcript, Brisbane, 4 July 2019, p 50.

¹⁶⁰² Public hearing transcript, Brisbane, 4 July 2019, p 85.

¹⁶⁰³ Submission 1891, p 16.

within subacute services to major tertiary hospitals through HHSs ‘contributes to a lack of transparency in expenditure’.¹⁶⁰⁴

Palliative Care Queensland noted that ‘the provision of funding to sub-acute services, without specific activity outcomes related to community-based investment, reduces incentive for funding to flow to rural and remote areas’.¹⁶⁰⁵ At the public hearing on 4 July 2019, Ms Carol Hope called for sustainable funding models in regional and remote areas to assist with equitable access for those populations.¹⁶⁰⁶

The Uniting Church in Australia Queensland Synod similarly submitted that the current funding approach leads to inconsistent service provision:

*The current funding model supplying specialist palliative care services in Queensland distributes funding to Hospital and Health Services, who then direct how this is used. While this decentralised approach has benefits in addressing local need, it has also led to inconsistencies in how funding is directed to people’s care in different parts of the state. For example, some Hospital and Health Service regions only focus support on the final six weeks of life, while others take a longer-term approach to providing care from the point of diagnosis. The latter approach is consistent with best practice in palliative care. This leads to inequitable service access across the state and within the South East corner.*¹⁶⁰⁷

Catholic Health Australia submitted that ‘the state funding models of care also create fragmentation of the system geographically, which significantly impacts equitable access to PC’. The following example was provided:

*For example, specialist inpatient PC [palliative care] providers in Brisbane South are unable to provide inpatient services to patients, many of whom are vulnerable and disadvantaged, in Brisbane Metro or the northside of Brisbane, regardless of where the closest inpatient service is located or the needs of the patient.*¹⁶⁰⁸

Dr Will Cairns advised that HHS determination of funding priorities has meant that it is up to clinicians to persuade decision-makers of the importance of palliative care:

*The development or otherwise of palliative care services across Queensland has often been dependent on the ability of clinicians to persuade their local or regional administrators that palliative care was a core part of their business and the luck of the draw in their clinical leaders who understood palliative care as an essential component of clinical services.*¹⁶⁰⁹

Ms Kathleen Forrester, Deputy Director-General, Strategy, Policy and Planning Division at Queensland Health, was asked for comment on Queensland Health’s approach which sees differing levels of palliative care provided across Queensland. She advised that:

*To some extent that will be the case for any health service, really—any particular type of clinical service—because each HHS is set up to respond particularly to its local needs given the existing infrastructure and arrangements that it has in place, so to some extent that is going to be the case for every service. The service that you deliver on the Gold Coast or in Metro South is very different to the service that you might be delivering in Thursday Island or Mount Isa.*¹⁶¹⁰

¹⁶⁰⁴ Submission 1891, p 15.

¹⁶⁰⁵ Submission 1891, p 16.

¹⁶⁰⁶ Public hearing transcript, Brisbane, 4 July 2019, p 81.

¹⁶⁰⁷ Submission 1268, p 26.

¹⁶⁰⁸ Submission 1249, p 5.

¹⁶⁰⁹ Submission 1940, p 16.

¹⁶¹⁰ Private briefing transcript, Brisbane, 6 December 2018, p 16.

Issues were also raised with the activity-based approach to funding. Palliative Care Queensland stated that hospital activity-based funding means that ‘all the public specialist palliative care services in Queensland rely on hospital activity to deliver community services through the health service’. Palliative Care Queensland stated that this is contrary to the notion that most people would prefer to be cared for at home.¹⁶¹¹

On the matter of budget and activity determination under HHS agreements, Dr Andrew Broadbent told the committee that the medical directors in HHSs are not given the opportunity to contribute to determining the budget, in part because others are involved in that process and because the funding is historical. Dr Broadbent stated:

*What happened last year continues. If I want to put in place change—and I do try that because there is a law of one per cent; I make a small adjustment to everything, whether that is a slight increase in staffing or a slight decrease—all of that requires about a two-year program to change.*¹⁶¹²

Dr Broadbent, a medical director of specialist palliative care on the Gold Coast, also told the committee that medical directors are not involved in choosing what activities are selected as part of the funding.¹⁶¹³ Dr Nick Buckmaster, Medical Director of General Medicine and Aged Care at Queensland Health, also commented on the inadequacy of the current funding model and frontline staff’s separation from setting the budget, stating:

*Although we are expected to provide medical leadership, and we do, at least in our health service the budget setting occurs away from us. The prioritisation of where funding is allocated tends to be tied to activity targets which do not reflect the needs of aged individuals nor palliative care. I welcome this inquiry because my hope is that it shines a light on the need for the ability to measure outcomes in aged care and in palliative care which are meaningful to the community and which then can have appropriate funding.*¹⁶¹⁴

Mr Peter Collins submitted that the current system ‘has funding mechanisms that incentivise activities rather than health outcomes – NDIS, Aged care (home and RACF) and palliative (both generalist and specialist) should not be an either-or proposition’.¹⁶¹⁵

Some inquiry participants raised concerns surrounding time-limited funding models or capped funding models.

The Uniting Church in Australia Queensland Synod advised that time-limited funding of specialist palliative care services creates gaps in the system, submitting:

*Funding gaps regularly arise when specialist palliative care models are focused into short timeframes at the end-of-life and have limited funding for allied health and other ancillary support. This leads to unmet needs that are also not met by other community support systems, such as the Commonwealth Home Support Program, which take a basic needs approach. In some instances there can be a heavy reliance on alternative programs when eligibility for services is stretched. In many cases, clients have to pay for their services, which can financially stretch families at the time of bereavement.*¹⁶¹⁶

¹⁶¹¹ Submission 1891, p 15.

¹⁶¹² Public hearing transcript, Southport, 10 September 2019, p 7.

¹⁶¹³ Public hearing transcript, Southport, 10 September 2019, p 7.

¹⁶¹⁴ Public hearing transcript, Southport, 10 September 2019, p 8.

¹⁶¹⁵ Submission 196, p 1.

¹⁶¹⁶ Submission 1268, p 26.

Catholic Health Australia similarly stated:

*In QLD there are also reported time-restricted access policies operating in non-CHA member public community PC services. In these instances, people can only access specialist community PC when they are within 3 months of the end of their life. Such restrictions should immediately be removed.*¹⁶¹⁷

Cancer Council Queensland referred to the discrepancy between the definition of early referral to palliative care and the current funding model, advising that ‘Clients accessing our services report their frustrations when they have life limiting illnesses and they ‘are not dying quick enough’ to fit the funding criteria’.¹⁶¹⁸

The issue of people accessing home-based or community-based palliative care being restricted by the current funding model was raised by a number of stakeholders. For example, Ms Carol Hope stated ‘that whilst most palliative care could happen in the community, the funding models are incongruent with supporting home based palliative care’.¹⁶¹⁹

Dr Broadbent explained that the current model of state funding means he cannot develop strategies to keep people out of hospital and have them receive palliative care at home instead, stating:

*We cannot change the structure of our funding because of how our state based funding is. I cannot create the community teams that I need to keep these people at home or create the package of care.*¹⁶²⁰

When asked about funding and the constraints it places on palliative care patients on being able to return home, Dr Broadbent provided the following:

*The false economy is staggering. Every day—twice a day, three times a day—I am seeing patients who could go home if we had appropriate packages of care or funding but they cannot. We just cannot give them the resources. It is not just nursing care. To keep somebody at home you need a variety of staff. That includes particularly skilled allied health staff and other doctors as specialists to assist the generalist doctors such as the GPs.*¹⁶²¹

As noted earlier, the Queensland Government announced midway through the inquiry that a further \$10 million over four financial years would be allocated to fund the seven non-government hospice services in Queensland. Some stakeholders raised issues with the amount of funding provided by the Queensland Government to these hospices prior to this announcement. According to PCQ, ‘Historically, this funding has been inequitable across the services and has not increased (beyond CPI) for at least a decade’.¹⁶²²

Reverend Linda McWilliam from Anglicare Southern Queensland had called for more funding for community hospices. She told the committee:

*Many other countries have a hospice community. In the UK, Canada and New Zealand there are lots of community hospices. We have a few in Queensland, but it seems to be very difficult to maintain them funding wise. There is never enough funding that comes apart from community funding and volunteers.*¹⁶²³

¹⁶¹⁷ Submission 1249, pp 5-6.

¹⁶¹⁸ Submission 1303, p 12.

¹⁶¹⁹ Public hearing transcript, Brisbane, 4 July 2019, p 81.

¹⁶²⁰ Public hearing transcript, Brisbane, 5 April 2019, p 9.

¹⁶²¹ Public hearing transcript, Southport, 10 September 2019, p 4.

¹⁶²² Submission 1891, p 17.

¹⁶²³ Public hearing transcript, Brisbane, 4 July 2019, p 76.

Following the Queensland Government's announcement, Ms Sue Manton, CEO of Little Haven Palliative Care, told the media 'Today marks the day we can finally let go of the day to day costs and concentrate on our long held visions...'.¹⁶²⁴

16.2.2.2 Commonwealth funding

Inquiry stakeholders raised two key issues in relation to the Australian Government's funding of palliative care – remuneration for GPs to provide services in RACFs and home settings, and the lack of funding for palliative care in RACF funding.

Funding palliative care by General Practitioners in the community and residential aged care facilities

Some inquiry stakeholders expressed concerns that existing Commonwealth funding arrangements had a detrimental impact on the provision of palliative care by general practitioners. This issue is also discussed in Chapter 7 in relation to RACF resident access to GP and other medical specialist services.

Palliative Care Queensland advised that there was 'little financial incentive' for GP engagement in home-based palliative care and that current funding was 'insufficient' to encourage GPs to visit RACFs where they are needed:

*There is little financial incentive for General Practice engagement in home-based palliative care. GP Home visits or visits to RACFs do not attract higher fees than standard consultations, despite taking the GP out of the office for long periods, reducing opportunities for multiple patient transactions. The current funding is insufficient to encourage GPs or Specialist Palliative Care teams to visit RACFs where they are needed. Palliative care interventions have demonstrated savings to clients, families and health services. Specialist palliative care interventions are less expensive compared to acute interventions including Intensive Care Unit (ICU) admissions. Further, palliative care can reduce emergency department presentations.*¹⁶²⁵

The AMA Queensland similarly submitted:

GPs report that they find it extremely difficult to treat their patients in RACFs due to limited organisational support at some RACFs and poor financial incentives. Many GPs are forced to relinquish giving care to these patients. Other GPs provide extra, unpaid, work to patients and their families by writing prescriptions out of hours and providing bereavement support.

*This is not a sustainable model of care. GPs need to be supported to provide care to patients in RACFs. The Queensland Government should lobby the Commonwealth Government for increased Medicare payments for GPs and other allied health groups to provide palliative treatment to patients in RACFs. Increased medical treatment in RACFs is an efficient way of treating patients and will relieve pressure on acute treatment beds in hospitals.*¹⁶²⁶

Catholic Health Australia also advised that '...there are significant inconsistencies in the ability of practitioners to claim Medicare Benefits Schedule (MBS) PC items and many PC-specific MBS items are considered to be under-remunerated'.¹⁶²⁷

From an RACF perspective, ACSA commented that access to GPs to carry out visits at short notice can often be problematic:

The Australian Medical Association Aged Care Survey 2017 identified more than 35 per cent of the doctors surveyed reported that they plan to not take on new patients in residential aged care,

¹⁶²⁴ Little Haven Palliative Care Inc., State Government Announces \$4m Funding over 4 years, <https://littlehaven.org.au/state-government-announces-4m-funding-over-4-years/>.

¹⁶²⁵ Submission 1891, p 16.

¹⁶²⁶ Submission 1233, pp 8-9.

¹⁶²⁷ Submission 1249, p 5.

reduce the number of visits, or stop completely, over the next two years, and the proportion of doctors visiting residential aged care services has dropped by 13.5% since 2015.

*This coupled with the requirement for GPs to visit more frequently due to rapid health changes as a palliating older person deteriorates can put additional pressure on residential and community aged care staff and impact on the quality of palliative care services for the older person.*¹⁶²⁸

The committee questioned whether these funding arrangements were resulting in an increased financial burden on the Queensland public health system including public hospitals and the emergency system. Dr Wakefield, Queensland Health, explained that ‘it is complex, but it is certainly the case’.¹⁶²⁹

Dr Wakefield explained that there were a number of important economic considerations when looking at GP funding models and the impacts that they have on service delivery. The first consideration related to the financial incentive for GPs to undertake palliative care work in an urban setting where there is a good supply of GPs:

*To what extent are they willing to engage in that sort of delivery into residential aged care, particularly if you are talking residential aged care, or even home care? How many GPs will provide care to their patients in their home through home visits and so on? At least at some level, even though the market for the supply of general practitioners is good in that urban model, the economics may or may not stack up for GPs.*¹⁶³⁰

Dr Wakefield continued that this resulted in a market failure which created ‘more difficulty and more dependency on publicly funded services’:

*If that market fails, and we think it is failing, then the ability to have that wraparound primary palliation ... falls over. That then creates more difficulty and more dependency on the publicly funded services, and it may often lead to the use of specialist care services where actually they are not really required for what the patient needs. They do not need a specialist, but that is our model and the market has failed.*¹⁶³¹

Dr Wakefield also reported a market failure resulting from a shortage of supply of GPs, compounded by lower rates in bulk-billing, in rural, regional and remote areas:

*In the remote areas and in the rural areas and even many of the regional areas, there is a market failure issue there with supply of GPs particularly and other areas of health. If GPs do not want to go there, there are not GPs. Those areas tend to have lower rates of bulk-billing because of the supply and demand, so that compounds the problem I think of getting that sort of care. That is where often the public system has to step in in many ways to provide services. Whilst it is a Commonwealth obligation, primary care and so on, it does not happen because there is no supply because it is market driven.*¹⁶³²

Dr Wakefield continued that funding can also be an issue in RACFs, advising that in situations where there was not sufficient professional support within the facility, the patient would end up being sent to the hospital:

The other thing is that within aged-care facilities themselves the economics can be an issue as well. Again, it is not the only issue, but certainly if the economics of private and not-for-profit residential aged care are such that they cannot or will not have the clinical support that they need—nurses on the ground particularly, as well as that visiting GP or responsive GP, especially

¹⁶²⁸ Submission 1285, p 6.

¹⁶²⁹ Private briefing transcript, Brisbane, 6 December 2018, p 8.

¹⁶³⁰ Private briefing transcript, Brisbane, 6 December 2018, p 8.

¹⁶³¹ Private briefing transcript, Brisbane, 6 December 2018, p 8.

¹⁶³² Private briefing transcript, Brisbane, 6 December 2018, p 9.

*in reactive circumstances—then that will fail and the patient will end up being sent to hospital.*¹⁶³³

Ms Forrester from Queensland Health advised the committee that the Australian Government had increased its budget in 2018 to improve the adequacy of palliative care in services and specialist palliative care in RACFS by adding \$32.8 million nationally over five years.¹⁶³⁴

Palliative care funding for residential aged care facilities

Queensland PHNs stated that ‘Residents of residential aged care facilities are often not afforded the same level of palliative care as people living in the broader community’ with one of the contributing factors being that ‘the current funding structure in residential aged care has no incentive for a palliative or end of life diagnosis with additional funding’.¹⁶³⁵ Queensland PHNs suggested that the Resource Utilisation and Classification Study recommendations are a way to rectify this and ensure that residential aged care funding for palliative care is sustainable into the future.¹⁶³⁶

Mr Francis Price, Director, Southern Cross Care told the committee:

*I just make the other comment in terms of palliative care that within an aged-care environment there is no special funding for palliative care. From an aged-care provider perspective...it would be far better for the individual, for their families and for our staff quite frankly to have that service continue within our facilities. Quite often the resources are not available within our facilities. People are transferred to hospital just purely through lack of resources.*¹⁶³⁷

The Uniting Church in Australia Queensland Synod commented that residential aged care services are not funded at the same level as hospitals and therefore do not have the same level of specialised care staff regularly available. They submitted:

As discussed by the Productivity Commission, funding for palliative care under the Aged Care Funding Instrument can only be accessed in the last week or days of a person’s life. In many cases, it is not viable to do a reassessment to access this funding and care is often provided without additional funds.

*In the absence of additional funding, Blue Care and Wesley Mission Queensland provides support for residents through existing resources and by partnering and working closely with Queensland Health funded specialist palliative care teams. However, we can only do this when resources allow and where external funding is available for services in a particular area.*¹⁶³⁸

Catholic Health Australia also commented on the Aged Care Funding Instrument (ACFI) being a funding barrier, submitting:

*The ACFI requires the person to be in the terminal phase of care, with a complex and administrative burdensome assessment process to access PC funding which often does not provide any additional funding due to the structure of the funding instrument. Moreover funding under ACFI is not intended to cover the cost of residents accessing specialist palliative care.*¹⁶³⁹

Catholic Health Australia disagreed with Queensland PHNs that the Resource Utilisation and Classification Study (RUCS) will rectify the issue, stating:

¹⁶³³ Private briefing transcript, Brisbane, 6 February 2018, p 8.

¹⁶³⁴ Private briefing transcript, Brisbane, 6 December 2018, p 9.

¹⁶³⁵ Submission 1301, p 8.

¹⁶³⁶ Submission 1301, p 8.

¹⁶³⁷ Public hearing transcript, Brisbane, 4 July 2019, p 64.

¹⁶³⁸ Submission 1268, p 25.

¹⁶³⁹ Submission 1249, p 5.

*Similarly, the proposed new funding model for funding care in aged care homes being developed following the Resource Utilisation and Classification Study is not intended to cover the cost of specialist palliative care services, though it is proposing a separately funded classification for residents with a palliative care plan.*¹⁶⁴⁰

16.3 Suggestions for improvement

16.3.1 Increased funding

As mentioned earlier, many stakeholders called for increased funding to ensure equitable and timely access to palliative care. The following are a sample of comments made on the need to increase funding.

The RACP advised that it has:

*recently called on the Australian Government to commit to secure, long-term funding to facilitate progress in end-of-life workforce development and quality of care and to ensure that national palliative care initiatives continue to be funded as part of mainstream health care. In light of the ongoing concerns regarding the capacity of the Queensland service and support system for palliative care and the projected need for all levels of palliative care to increase in line with the state's growing and aging population, the RACP calls on the Queensland government to continue to engage with the Australian Government to commit appropriate funding to meet the mounting demands on the palliative care system across the state.*¹⁶⁴¹

The AMA Queensland commented on recent announcements regarding the Queensland Government's spending on palliative care, stating:

*We are calling for the Queensland government to sufficiently resource palliative care services. In the budget announcements only a few weeks ago there was a positive first step, which I call a deposit, of \$17 million—and we all know that \$17 million is not going to go very far.*¹⁶⁴² *...a massive, genuine, non-tokenistic contribution to palliative care that includes training, education and making sure that the right doctors and specialists and nurses and allied health are in those rural and remote areas.*¹⁶⁴³

To ensure palliative care needs and preferences are met, ACSA recommended:

- *Increased and more timely funding for the provision of palliative care services to enable older people to have the death experience of their choice, whether they choose to have that experience in their own home or in a residential aged care service. Increased funding can assist:*
 - *The upskilling of the aged care workforce.*
 - *Increased access to palliative care resources.*
 - *Increased access to palliative care equipment.*¹⁶⁴⁴

Stakeholders also made a range of recommendations to improve the state and federal funding models for palliative care services. These recommendations are outlined in the sections below.

¹⁶⁴⁰ Submission 1249, p 5.

¹⁶⁴¹ Submission 1203, p 3.

¹⁶⁴² Public briefing transcript, Brisbane, 4 July 2019, p 32.

¹⁶⁴³ Public briefing transcript, Brisbane, 4 July 2019, p 32.

¹⁶⁴⁴ Submission 1285, p 7.

16.3.2 Queensland Government funding

A number of stakeholders called for a statewide strategy for palliative care provision as a means of addressing concerns about palliative care not receiving sufficient attention in HHS allocations.

Palliative Care Queensland recommended that the Queensland Government:

*Develop and implement a Queensland Palliative Care Strategy based on the National Palliative Care Strategy which links to the Statewide Strategy for End-of Life Care but includes specialist palliative care, generalist palliative care and public health palliative care. This strategy should include services delivered outside of Queensland Health (including Private, NGO services and community organisations) and should highlight the value of Specialist Palliative Care as the providers of leadership, clinical expertise and strategic input.*¹⁶⁴⁵

The AMA Queensland advised that it had ‘for some time now’ been calling for the Queensland Government to develop a palliative care strategy.¹⁶⁴⁶

When asked about the importance of a statewide strategy, Dr Stephen Duckett, Director of the Health Program at the Grattan Institute, advised that the state government needs to make clear its expectations:

*For example, it has to say, ‘We expect every HHS to develop its own palliative care plan’ so that it makes sure it is going to deal with hard-to-reach populations, both Indigenous populations and people from culturally and linguistically diverse backgrounds. How is it going to make sure that it is not a city-centric plan or a regional city-centric plan and that services are available everywhere throughout the HHS? The HHSs themselves have to have palliative care plans that are quite operational, that say how they are going to do it.*¹⁶⁴⁷

Dr Duckett also argued for performance measurements to be attached to funding that measure the extent to which palliative care is meeting the needs of Queenslanders’.¹⁶⁴⁸

Dr Will Cairns called for the mandating of service levels to support equitable access to palliative care:

*Many of the people who chose to remain in or return to their home community when they are approaching their death have to accept the trade-off cost that benefits of being at home are offset by a reduced quality of care. It is long overdue that appropriate levels of palliative care services be mandated in service agreements with all HHSs.*¹⁶⁴⁹

The Uniting Church in Australia Queensland Synod submitted that to meet future demand, funding for expanded early intervention, community-based, multidisciplinary specialist teams must be considered, which should include:

*...guidelines to ensure each Hospital and Health Service region provides access to care following people’s diagnosis and removes reliance on Commonwealth programs not designed to meet these needs.*¹⁶⁵⁰

Dr Greg Parker, a palliative medicine specialist based in Brisbane, told the committee that Queensland has a clinical services capability framework that has been mandated by Queensland Health and is applicable in each HHS, but it is self-reported. Dr Parker provided the following example:

¹⁶⁴⁵ Submission 1891, p 18.

¹⁶⁴⁶ Public briefing transcript, Brisbane, 4 July 2019. P 32.

¹⁶⁴⁷ Public hearing transcript, Brisbane, 23 August 2019, p 62.

¹⁶⁴⁸ Public hearing transcript, Brisbane, 23 August 2019, p 61.

¹⁶⁴⁹ Submission 1940, p 16.

¹⁶⁵⁰ Submission 1268, p 33.

*For example, in Rockhampton, there is a level 5 cancer service...At the moment it is self-reporting. They talk about a level 5 palliative care service. There is no palliative care physician at all. There is a bits-and-pieces patchwork approach to delivering palliative care. I think we need to make the system accountable for that.*¹⁶⁵¹

There was also a call by some stakeholders to protect money for palliative care, so that the funds received are not redirected to the other sub-acute care specialties to the detriment of palliative care. For example, PCQ recommended that the administration of state-funded palliative care services be reviewed, specifically the positioning of specialist palliative care services within subacute services, and that a stand-alone funded service line situated in acute care with requirement for networks to subacute and community care be considered.¹⁶⁵²

Academics from the University of Queensland submitted:

*Funding for palliative care is often seen as 'low hanging fruit' – it does tend to get cut but must be protected to ensure equity for all Queenslanders and Australians. These funding cuts have led to limited palliative care availability for many Australians.*¹⁶⁵³

...

*Monies now provided and expected increases in the future for palliative care must be protected and not able to be diverted or repurposed by individual Health and Hospitals districts. (Specific ongoing funding supporting hospital-primary care integration should be made available).*¹⁶⁵⁴

Dr Stephen Duckett proposed a funding model based on his research which recommended that payment models for palliative care move towards activity based funding using agreed classification and uncapped funding with performance monitoring, which should make explicit use of performance metrics and reporting.¹⁶⁵⁵ The table below details the proposed desirable characteristics of palliative care funding arrangements.

Table 22: Desirable models of palliative care funding

Current models	More desirable model
Per-diem or fee-for-service payment	Activity based funding using an agreed classification
Capped funding	Uncapped funding with performance monitoring
Separate funding mechanisms for different site of care or death	Funding arrangements designed in light of policy objectives to encourage death in preferred location. Funding could be separate for different sites but must be aligned to reduce incentives for providers to choose site of care inappropriately and to ensure policy objectives are achieved.
Regular use of out of pocket payments	Reduced use of out of pocket payments
No, or implicit, performance metrics	Explicit use of performance metrics and reporting, potentially including use as part of a pay for performance program.

Source: Submission 4, the Grattan Institute, p 2.

¹⁶⁵¹ Public hearing transcript, Brisbane, 5 April 2019, p 13.

¹⁶⁵² Submission 1891, p 4

¹⁶⁵³ Submission 1219, p 6.

¹⁶⁵⁴ Submission 1219, p 7.

¹⁶⁵⁵ Public briefing transcript, Brisbane, 23 August 2019, p 60.

Dr Duckett stated in his submission that the uncapping of palliative care funding was of particular importance, stating:

*Uncapped activity based funding for palliative care is not a significant budget risk as palliative care demand is naturally capped by need related to the number of deaths. In any event, good palliative care reduces the demand on other more expensive services.*¹⁶⁵⁶

Palliative Care Queensland referred to Dr Duckett's research, stating:

*Hospital-based palliative care, funded under activity based funding arrangements, attracts funding for hospital admissions, which incentivised emergent hospital usage rather than community based services. In contrast, community or home based care is funded on a population basis so additional clients do not attract additional funding. The different funding mechanisms thus create a greater incentive for admissions to hospitals than for community based treatment.*¹⁶⁵⁷

To address the above, PCQ stated that 'it is critical that equally flexible funding models are developed that promote seamless interface between hospital and community care'.¹⁶⁵⁸ Palliative Care Queensland called for a needs-based funding model for specialist palliative care to be developed, which includes packages of care instead of time-limited funding models.¹⁶⁵⁹

The Uniting Church in Australia Queensland Synod commented on the tendering of palliative care services, advising that '[t]endering these services to not-for-profit organisations is a positive step towards providing responsive, holistic and cost effective community-based services'. The Uniting Church also stated:

*We believe there is significant value to be gained by Queensland Health when contracting specialist palliative care services to organisations such as Blue Care and Wesley Mission Queensland. When funded appropriately, community-based programs can operate flexibly to respond to people in their setting of choice, provide high quality care, and deliver comparable outcomes to publically funded services. Community-based services also operate more cost effectively than government services. However, it is important that tendering processes value the contributions of community organisations and have strong transition mechanisms in place if contracts change.*¹⁶⁶⁰

Palliative Care Queensland also recommended that the Queensland Government continue funding:

- *In hospital specialist palliative care services*
- *Existing consultative and integrated Palliative Care services*
- *Home-based services to continue to improve client outcomes and increase chance of clients dying at home.*¹⁶⁶¹

Palliative Care Queensland also made the following recommendations regarding funding:

- *ensure that funding is easier to access in a timely manner, particularly for home-based care and aged care*¹⁶⁶²

¹⁶⁵⁶ Public briefing transcript, Brisbane, 23 August 2019, p 60.

¹⁶⁵⁷ Submission 1891, p 17.

¹⁶⁵⁸ Submission 1891, p 17.

¹⁶⁵⁹ Submission 1891, p 18.

¹⁶⁶⁰ Submission 1268, pp 26-27.

¹⁶⁶¹ Submission 1891, pp 4-5.

¹⁶⁶² Submission no. 1891, p 5.

- *ensure funding is equitable, particularly for people in rural and remote areas and for those under 65 years of aged*¹⁶⁶³
- *provide Queensland Health innovation funding for sustainable innovation, ie proof of concept, in service delivery that integrates services in state, federal and private sectors*
- *increase funding for community residential hospices for respite options and end-of-life care - supported by local GPs and with medical support provided to GPs via Specialist Palliative Care Physicians*
- *ensure sustainable funding is available for hospices, private and non-profit palliative care services throughout Queensland*
- *provide support and funding for community education and engagement programs*
- *continue funding for the Office of Advance Care Planning to support the advance care planning program across Queensland and provide oversight and build the evidence base*
- *provide support and funding for advance care planning initiatives*
- *continue funding for the Centre for Palliative Care Research and Education to support sustainable and consistent education in palliative care*

16.3.3 Australian Government funding

A number of stakeholders called for a review of MBS item numbers to enable GPs to undertake RACF and home visits while being appropriately compensated. For example, Queensland PHNs called for:

*MBS item numbers that better enable both generalist and specialist palliative care to be provided across the health sector. This includes changes to enable general practitioners and nurse practitioners to facilitate family meetings and advance care planning discussions, and support home visits, after hours support and palliative care in residential aged care.*¹⁶⁶⁴ *Improved funding and support for general practitioners to provide palliative care in the community.*¹⁶⁶⁵

The Uniting Church in Australia Queensland Synod advised the committee that:

*At a federal level, improvements in Medicare funding for GP home visits and new palliative care billing items would significantly improve in-community GP support and engagement with patients. This work could also be supported with additional state-funded community-based nursing and allied health support.*¹⁶⁶⁶

Dr Bruce Willett, Chair of the Royal Australian College of General Practitioners, added to the idea of better remuneration for GPs, stating:

*It is not just increasing the rebate. The idea of block funding is a really important concept as well. A lump of funds to provide a service to that patient in a more holistic sense is probably the way to go.*¹⁶⁶⁷

Palliative Care Queensland recommended the Queensland Government support and advocate for a review of Medicare Item number remuneration for:

- *GPs doing home visits or RACF visits*

¹⁶⁶³ Submission no. 1891, p 5.

¹⁶⁶⁴ Submission 1301, p 10.

¹⁶⁶⁵ Submission 1301, p 10.

¹⁶⁶⁶ Submission 1268, p 22.

¹⁶⁶⁷ Public hearing transcript, Brisbane, 4 July 2019, p 8.

- *Specialist Palliative Care Nurse Practitioners undertaking home and RACF visits (currently under review)*
- *Outreach Palliative Care Services to support rural and remote areas with the greatest disadvantage, e.g. Palm Island and Charters Towers.*¹⁶⁶⁸

Other suggestions by stakeholders on how both state and federal funding models should be amended in order to improve the delivery of palliative care in Queensland included:

- *a move from siloed funding mechanisms to funding models that are equitable and more supportive of palliative care provision*¹⁶⁶⁹
- *a central or regionalised equitable population-based funding framework*¹⁶⁷⁰
- *funding models that recognise the need for essential palliative care services for patients and families 24 hours/7 days per week*¹⁶⁷¹
- *financial models for funding new community-based hospices that draw upon public, private or mixed funding models*¹⁶⁷²
- *consistent funding levels for nurse practitioners in specialist palliative care responses*¹⁶⁷³
- *an individualised funding model, consistent with consumer-directed care approaches in the broader aged care and disability sectors.*¹⁶⁷⁴

The AMA Queensland called upon the Federal Government to increase its funding of the National Palliative Care scheme as part of an expected 2017 review.¹⁶⁷⁵

Committee comment

Funding for end-of-life care and palliative care

Funding is a key issue which impacts on many aspects of the delivery of palliative care including provision of services, workforce and training development, education and public awareness, resourcing, infrastructure and coordination of services.

The committee heard from stakeholders throughout the inquiry that inadequate funding, coupled with the current funding models, is impacting on equitable and timely access to good quality palliative care for those who are eligible. This is particularly so for those living in rural and remote areas, residents of residential aged care facilities and those wanting to receive palliative care at home. It is simply not good enough that your postcode, your diagnosis or your place of residence could impact upon your ability to access palliative care.

Australian Government funding and delivery of palliative care

A number of inquiry participants stated that palliative care funding is not keeping up with current demand, let alone preparation for the future demand for palliative care. Stakeholders indicated that Australian Government funding for palliative care needs to be responsive to the growing population

¹⁶⁶⁸ Submission 1891, p 4.

¹⁶⁶⁹ Submission 1301, p 11.

¹⁶⁷⁰ Submission 1212, p 8.

¹⁶⁷¹ Submission 1252, p 7.

¹⁶⁷² Submission 1268, p 30.

¹⁶⁷³ Submission 1268, p 6.

¹⁶⁷⁴ Submission 1268, p 34.

¹⁶⁷⁵ Submission 1233, attachment, p 5.

and the health demographic to enable person-centred care to be provided to all those who seek it. Increased funding was a key recommendation by stakeholders

The remuneration received by general practitioners for visiting residential aged care facilities or palliative care patients at home was another key issue. It was clear to the committee that general practitioners are not properly remunerated for such visits, jeopardising the care these patients receive. These patients either risk receiving a reduced quality of care or are forced to go to hospital, where they may not wish to spend their final days. Hospitalisation subsequently results in an economic burden to the Queensland Health Service.

Similarly, the funding provided to residential aged care facilities via the Aged Care Funding Instrument does not provide for palliative care to be delivered in residential aged care facilities, leaving residents with little option but to attend hospital or risk receiving inadequate care.

The committee acknowledges that its suggested improvements are the responsibility of the Australian Government.

The committee has already made recommendations under the aged care section of this report for the Australian Government to review Medicare Benefits Scheme item numbers to ensure equitable access to general practitioners services for those living in residential aged care facilities or at home.

The committee has also recommended that the Australian and Queensland governments collaborate to consider co-funding integrated palliative care to those in residential aged care facilities, hospice or those who would prefer to receive their care at home.

Recommendation 53 Increased Australian Government funding for palliative care

The committee recommends that the Australian Government increase the amount available through subacute funding for the delivery of palliative care to address the unmet need for services.

Recommendation 54 Increased Queensland Government funding for palliative care

The committee recommends that the Queensland Government increase its funding for palliative care in Queensland.

Recommendation 55 Options to prevent palliative care funding being diverted

The committee recommends that the Queensland Government examine options to ensure that palliative care funding is not diverted to other subacute areas.

Recommendation 56 Palliative and end-of-life care for residential aged care residents

The committee recommends that the Australian Government properly fund palliative care and end-of-life care services provided to residents living in private homes or in residential aged care facilities so residents can access the clinical care, nursing and specialist palliative care services they require. This will involve providing greater flexibility in the home care package system and a redesign of the Aged Care Funding Instrument to incorporate funding for palliative and end-of-life care.

Committee comment

Queensland Government funding and delivery of palliative care

The committee commends the Queensland Government's increase in palliative care funding to palliative care providers in the non-government organisation sector to assist with the delivery of community-based palliative care.

The committee also commends the Queensland Government's \$17 million funding commitment to increase palliative care services in regional and remote areas.

Likewise, the committee commends the Queensland Government's funding announcement in October 2019 of \$8.25 million over five years to Queensland's only children's hospice, Hummingbird House.¹⁶⁷⁶

However, more needs to be done to ensure hospital and community-based palliative care can be delivered to those in need according to their preferences, particularly those outside of the South East corner of Queensland.

Current palliative care funding is bundled with the funding for other sub-acute services, resulting in a lack of transparency regarding Queensland Health's palliative care budget and expenditure. It is up to each Hospital and Health Service how they distribute that funding between the sub-acute services. While the committee understands that there are benefits to designing health services to meet local needs, the evidence provided by stakeholders indicated that this approach leads to the varying provision of palliative care services.

Furthermore, there is no mandated policy or performance measurements attached to the funding to Hospital and Health Services for the delivery of palliative care as part of their agreement. As a result, the committee heard that palliative care delivery is inconsistent and dependent on the Hospital and Health Service administrator's recognition of the importance of palliative care. The committee was surprised to hear that there were no guidelines or performance standards, and that medical directors are not involved with budget or activity decisions when preparing the Hospital and Health Service Annual Service agreements.

The committee notes the recommendations on funding made in the report tabled by the Health and Community Services Committee in May 2013, titled *Palliative and community care in Queensland: toward person centred care*.

The first of these recommendations was that the Minister for Health ensure that Queensland Health report on palliative care service provision and expenditure as part of its annual reporting, including a breakdown of funding sources.¹⁶⁷⁷ Implementation of such a recommendation would help provide the transparency that Palliative Care Queensland has stated was lacking.

The Queensland Government at the time did not accept the recommendation, stating 'The Queensland Government considers that the current level of reporting strikes a balance between transparency and the burden of reporting which can have an impact on front line services'.¹⁶⁷⁸

Given the call for greater transparency on funding, particularly in relation to the how the Hospital and Health Services distribute funding between the sub-acute services, the committee considers that the current Queensland Government should re-consider this recommendation. If the calls to separate palliative care funding from the funding for other sub-acute services as outlined below is not heeded, then this recommendation becomes even more important in terms of accountability for the provision of palliative care in Queensland.

The second of these recommendations was that the Minister for Health write to the Commonwealth Minister for Health in support of the Senate committee's Recommendation No. 2 that palliative care

¹⁶⁷⁶ The Honourable Steven Miles, Minister for Health and Minister for Ambulance Services, 'Hummingbird House receives big funding boost from Qld Government', media release, 11 October 2019, <http://statements.qld.gov.au/Statement/2019/10/11/hummingbird-house-receives-big-funding-boost-from-qld-government>.

¹⁶⁷⁷ Health and Community Services Committee, *Palliative and community care in Queensland: toward person centred care*, May 2013, p 112, <https://www.parliament.qld.gov.au/documents/committees/HCS/2012/PaCareHAAC/rpt-022-17May2013.pdf>.

¹⁶⁷⁸ Government Response to Recommendations Health and Community Services Committee Palliative and community care in Queensland: towards person-centred care (Report No. 22), p 15, <https://www.parliament.qld.gov.au/documents/tableOffice/TabledPapers/2013/5413T3213.pdf>.

funding should be separated from ‘subacute’ funding.¹⁶⁷⁹ Stakeholders to this inquiry also called for palliative care funding to be separated to prevent sub-acute funding from being distributed to support other sub-acute services to the detriment of palliative care provision.

Once again, the Queensland Government at the time did not accept the recommendation, stating:

*Palliative care currently has its funding structure within the sub-acute and non-acute classification system. This system includes 12 different payment categories for of [sic] overnight palliative care. In addition, there is a separate payment which applies to outpatient palliative care. Separating funding from other sub-acute services is likely to diminish the importance of sub-acute services as well as palliative care services when compared with other health services.*¹⁶⁸⁰

It is not immediately obvious to the committee how separating palliative care funding from other sub-acute services funding would diminish the importance of either palliative care or the remaining sub-acute services. During the inquiry, the committee repeatedly heard about the importance of providing good quality palliative and end-of-life care, and the difficulties in providing equitable, person-centred care under the current funding models.

To ensure all Queenslanders are able to access good palliative care, regardless of their location or diagnosis, adequate funding needs to be allocated, along with service guidelines and performance measurements to direct the funding. Separate funding would ensure funds couldn’t be re-distributed to other services and would allow for specific measurement of the implementation of those funds.

The third, and last, recommendation in relation to funding made by the Health and Community Services Committee was that the Minister for Health write to the Commonwealth Minister for Health for two purposes: to support the Senate committee’s Recommendation No. 3 that the Independent Hospital Pricing Authority establish a palliative care advisory committee to advise on appropriate costing of palliative care services; and propose that the Independent Hospital Pricing Authority ensure that activity based funding does not limit the provision of palliative care consultancy and liaison with primary health providers, services in community settings, and services delivered by multi-disciplinary teams.¹⁶⁸¹

This recommendation was also rejected by the then-state government. Besides advising that an advisory group was not considered necessary to manage palliative care costing issues, the state government at the time advised that the Independent Hospital Pricing Authority list of in-scope public hospital services includes home and community based palliative care services, including palliative care day hospices, where it can be shown that such services are:

- *directly related to an inpatient admission or emergency department attendance*
- *intended to substitute directly for an inpatient admission or emergency department attendance*

¹⁶⁷⁹ Health and Community Services Committee, *Palliative and community care in Queensland: toward person centred care*, May 2013, p 113, <https://www.parliament.qld.gov.au/documents/committees/HCS/2012/PalCareHAAC/rpt-022-17May2013.pdf>.

¹⁶⁸⁰ Government Response to Recommendations Health and Community Services Committee Palliative and community care in Queensland: towards person-centred care (Report No. 22), p 15, <https://www.parliament.qld.gov.au/documents/tableOffice/TabledPapers/2013/5413T3213.pdf>.

¹⁶⁸¹ Health and Community Services Committee, *Palliative and community care in Queensland: toward person centred care*, May 2013, p 115, <https://www.parliament.qld.gov.au/documents/committees/HCS/2012/PalCareHAAC/rpt-022-17May2013.pdf>.

- *expected to improve the health or better manage the symptoms of persons with a physical or mental health conditions who have a history of frequent hospital attendance or admissions.*¹⁶⁸²

Activity-based funding was raised as an issue again during this inquiry, including concerns about the ‘incentivisation’ of hospital use over community-based services. On the evidence provided to the committee, current funding models don’t allow for comprehensive, flexible delivery of palliative care. The committee believes that funding for Hospital and Health Services and community-based services needs to be aligned to ensure that hospital use isn’t incentivised over community based services as a result of activity-based funding.

Stakeholders also raised concerns about time-limited funding models, and the committee agrees that such an approach doesn’t harmonise with the objective of person-centred, needs-based care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness. Hence, the committee supports the recommendation that the Queensland Government develop a needs based funding model for specialist palliative care which includes packages of care instead of time-limited funding models. The committee considers this should be considered by the Queensland Government as part of a broader review of palliative care.

Recommendation 57 Clinical capability framework for palliative care

The committee recommends that the Queensland Government, as a matter of urgency, mandate the application of the Clinical Services Capability Framework for Public and Licensed Private Health Facilities for palliative care planning and delivery by all Hospital and Health Services as part of their funding agreement, and monitor Hospital and Health Service performance in meeting this framework with explicit use of performance metrics and reporting.

Recommendation 58 Funding for specialist palliative care

The committee recommends that the Queensland Government consider as part of any broader review whether to develop a needs-based funding model for specialist palliative care which includes packages of care instead of time-limited funding models.

¹⁶⁸² Government Response to Recommendations Health and Community Services Committee Palliative and community care in Queensland: towards person-centred care (Report No. 22), p 16, <https://www.parliament.qld.gov.au/documents/tableOffice/TabledPapers/2013/5413T3213.pdf>.

17 The palliative care workforce

17.1 Current workforce situation

In Queensland, the palliative care workforce is made up of several health professions. This includes ‘specialist palliative medicine physicians, nurses, GPs, allied health, pharmacists other medical specialists (such as oncologists and geriatricians) and other health workers, support staff and volunteers’.¹⁶⁸³

The table below summarises the key characteristics of the primary palliative care workforce in Queensland.

Table 23: Palliative care workforce

Nursing – Current Supply
<ul style="list-style-type: none"> • 704 registered and enrolled nurses whose primary role is in palliative care • Majority work in public health system, within a hospital setting, followed by community setting and hospice. • Workforce clustered in SEQ

Source: Queensland Health, 2019, *Palliative Care Services Review – Key Findings*, pp 26-28.

17.1.1 What is considered an ‘adequate’ workforce and how is demand being met?

The Palliative Care Services Review of the palliative care sector stated that, while there have been moderate increases to some of Queensland’s palliative care workforce over recent years, this was offset by an ageing workforce and a distribution of staff that favours South East Queensland.¹⁶⁸⁴

The Palliative Care Services Review noted that as pressure continues to grow on the health system in response to service demand, consumer expectations and an aging population, so will the demand for workforce models and skills that can adapt to changing circumstances’.¹⁶⁸⁵

17.1.1.1 Nursing

The Palliative Care Services Review quoted the Australian Health Practitioners Regulation Authority’s 2017 *National Health Workforce survey*, which identified that there are 704 registered nurses and enrolled nurses across Queensland whose primary role is in palliative care, with the majority working in the public health system. Most of these nurses work in a hospital setting, followed by a community health care service setting and hospice. There is a clustering of the workforce in South East Queensland.¹⁶⁸⁶

The Palliative Care Services Review reported that annual growth for palliative care nurses in Queensland has exceeded five per cent between 2013 and 2016. In keeping with past trends, modelling shows the need for 70 additional nurses per annum in the short term to 2021, and 74 additional nurses per annum over a longer horizon to 2026.¹⁶⁸⁷

With just over one third of the workforce aged 55 years and over, it is not surprising that a large proportion of palliative care nurses expressed their intention to retire over the coming decade.¹⁶⁸⁸

¹⁶⁸³ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, p 26.

¹⁶⁸⁴ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, p 26.

¹⁶⁸⁵ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, p 26.

¹⁶⁸⁶ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, p 26.

¹⁶⁸⁷ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, p 26.

¹⁶⁸⁸ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, p 27.

17.1.1.2 *Palliative medicine specialists*

The Palliative Care Services Review advised there are 49 palliative medicine specialists practising in Queensland, the majority of whom work in a hospital setting of the public health system. The greatest number of specialists are found at Metro North, followed by Metro South, Gold Coast and Townsville HHSs.¹⁶⁸⁹

Queensland experienced remarkable growth in palliative medicine specialists of approximately 80 per cent between 2013 and 2017. However, modelling suggests a large undersupply of palliative medicine specialists over the coming decade.¹⁶⁹⁰ Modelling undertaken by Queensland Health resulted in a projected shortfall of 23 per cent in 2021 increasing to 32 per cent in 2027.¹⁶⁹¹

Twenty of the state's palliative medicine specialists have expressed intention to retire within the next 10 years, and of these, 13 intend to retire within four years.¹⁶⁹²

17.1.1.3 *Allied health professionals*

While Queensland's allied health workforce participated in the *2017 Australian Health Practitioners Regulation Authority survey*, only a small number of practitioners nominated their primary role as being in palliative care (n=<10). Hence, because of such small numbers, this information could not be reported and used for reasons of confidentiality.¹⁶⁹³

17.1.2 What strategies are in place to support workforce development?

The palliative care workforce is dealing with a number of issues including: the ageing of staff, increasing demand for services, shortages of medical and nursing staff trained in palliative care, and the concentration of trained staff in South East Queensland.

The committee did not receive evidence relating to a specific palliative care workforce strategy; however, the Palliative Care Services Review identified a number of high-level workforce strategy documents related to the health sector. These included:

- *My health, Queensland's future: Advancing health 2026*, which identified workforce shortages and the inequitable distribution of the state's health workforce. It also acknowledged the need for Queensland Health to explore new and innovative ways of delivering services, including the use of 'different types of workers or new technologies'.¹⁶⁹⁴
- *Queensland Health Snapshot, Advancing health service delivery through workforce: A strategy for Queensland 2017-2026*, which seeks to deliver a quality, consumer-centred healthcare through a capable, organised and engaged workforce and sets out high level focus areas and strategies.¹⁶⁹⁵
- *Advancing rural and remote service delivery through workforce: A strategy for Queensland 2017-2020* – which sets out overarching priorities for building a rural and remote health workforce.

¹⁶⁸⁹ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, p 27.

¹⁶⁹⁰ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, p 27.

¹⁶⁹¹ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, p 27.

¹⁶⁹² Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, p 27.

¹⁶⁹³ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, p 28.

¹⁶⁹⁴ Queensland Health, *My health, Queensland's future: Advancing health 2026*, p 17; https://www.health.qld.gov.au/__data/assets/pdf_file/0025/441655/vision-strat-healthy-qld.pdf,

¹⁶⁹⁵ Queensland Health, *Snapshot, Advancing health service delivery through workforce: A strategy for Queensland 2017-2026*, https://www.health.qld.gov.au/__data/assets/pdf_file/0038/657992/QH959-advancing-health-service-snapshot.pdf

The strategy acknowledges the challenges and the need for innovative models of care including the need for contemporary supporting infrastructure and processes.¹⁶⁹⁶

- Evidence, research and analysis contained in these strategic documents supports the finding from the Palliative Care Services Review that supporting and growing the palliative care workforce is a critical component of ensuring there is a high quality palliative care system in Queensland.¹⁶⁹⁷

The Palliative Care Services Review's literature review also identified a need to increase workforce capacity to deliver palliative care as a key area of priority for the future.¹⁶⁹⁸ The importance of investing in a skilled and capable palliative care workforce was also highlighted within the *National Palliative Care Strategy*.¹⁶⁹⁹

The availability of an adequate number of capable palliative care staff is the basis of Standard nine of Palliative Care Australia's *National Palliative Care Standards*. This stipulates that staff should be qualified and supported in their roles and to undertake further training and development. Supporting guidelines note that Palliative Care Australia has set a benchmark of two full time equivalent specialist palliative care physicians per 100,000 population.¹⁷⁰⁰ With Queensland's estimated resident population of over five million, and 49 palliative medicine specialists practising in Queensland, the state currently has a deficit of approximately 50 specialist palliative medicine physicians when compared to this benchmark. Evidence provided to the committee indicates that deficits are particularly prominent in areas outside of South East Queensland. A key need identified focusses on the importance of supporting the sector to implement staff attraction and retention strategies to address workforce shortages, as well as education and training to address capability issues and ensure the delivery of quality services.¹⁷⁰¹

17.1.3 Current workforce education and training

17.1.3.1 Formal medical training

Medical specialists must complete post-graduate specialist training to become a palliative medicine physician. Palliative medicine specialists are required to have completed three years of full-time equivalent training in either a paediatric or adult setting under the supervision of a palliative care physician. Successful trainees gain the qualification of Fellow of the Royal Australasian College of Physicians (FRACP)/Fellowship of the Australasian Chapter of Palliative Medicine (FACHPM), and are accredited to practise as a palliative medicine physician in Australia or New Zealand. Medical practitioners may also complete a six month Clinical Diploma in Palliative Medicine, but this qualification does not result in specialist accreditation.¹⁷⁰²

¹⁶⁹⁶ Queensland Health, *Advancing rural and remote service delivery through workforce: A strategy for Queensland 2017-2020*, https://www.health.qld.gov.au/__data/assets/pdf_file/0039/672978/rural-remote-workforce-strategy.pdf, p 5.

¹⁶⁹⁷ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 35.

¹⁶⁹⁸ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 35.

¹⁶⁹⁹ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, p 2, <https://www.health.gov.au/sites/default/files/national-palliative-care-strategy-2018.pdf>.

¹⁷⁰⁰ Palliative Care Australia, *National Palliative Care Standards 5th edition 2018*, p 21, https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/11/PalliativeCare-National-Standards-2018_Nov-web.pdf.

¹⁷⁰¹ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 34.

¹⁷⁰² Australian Institute of Health and Welfare, *Palliative care services in Australia*, <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce>.

Nurses may complete a variety of short or more comprehensive courses (including postgraduate certificate and Masters qualifications) if they wish to work in the field of palliative care, and postgraduate qualifications are generally required for nurses working in specialist palliative care services.¹⁷⁰³

17.1.3.2 Government-funded training and development programs

In addition to the formal training described above, the committee heard about a number of programs developed to provide access to information and guidance on delivering good quality palliative care by a range of health care workers and volunteers.

Australian Department of Health

The Australian Department of Health funds a range of national palliative care initiatives and programs, which includes programs that focus on education and training. Some of these are outlined below.

PCC4U

PCC4U is a national palliative care program which aims to improve the skill and confidence of the health workforce to work with people with palliative care needs by promoting the integration of palliative care training within all health undergraduate, entry-to-practice, and relevant post-graduate curricula.¹⁷⁰⁴

Program of Experience in the Palliative Approach (PEPA)

The Program of Experience in the Palliative Approach (PEPA) ‘takes a strategic approach to education and training of the health workforce and delivers programs for priority health care provider groups across primary, secondary and tertiary settings’.¹⁷⁰⁵

Specifically, PEPA aims to enhance the capacity of health professionals to deliver a palliative care approach through their participation in either clinical placements in specialist palliative care services or interactive workshops.

Professor Patsy Yates explained that PEPA is ‘targeted at people who are not specialists but who work in an acute care setting, or in aged-care setting, or in the community, to have an immersion experience in a specialist palliative care setting’.¹⁷⁰⁶ Mr John Haberecht advised that PEPA will provide people with up to a four-day observational placement with a specialist palliative care team, and provides face-to-face and some online education.¹⁷⁰⁷

Quality of Care Collaborative Australia

The Quality of Care Collaborative Australia (QuoCCA) was designed to deliver paediatric palliative care education to health professionals in urban, rural, regional and remote areas who may care for children and young people with palliative and end-of-life care needs.¹⁷⁰⁸ The Quality of Care Collaborative Australia 2 (QuoCCA 2) has now commenced and ‘seeks to bring about improvements in skills, knowledge and confidence of health professionals involved in delivery of paediatric palliative care across Australia, through delivery of education and research’. Any health professional, including medical, nursing and allied health, or local community supports (e.g. chaplains, teachers, funeral

¹⁷⁰³ Australian Institute of Health and Welfare, Palliative care services in Australia, <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce>.

¹⁷⁰⁴ Palliative Care Curriculum for Undergraduates, About PCC4U, <https://pcc4u.org.au/about/>.

¹⁷⁰⁵ Program of Experience in the Palliative Approach, What is PEPA?, <https://pepaeducation.com/about-pepa/what-is-pepa/>.

¹⁷⁰⁶ Public hearing transcript, Brisbane, 5 July 2019, p 39.

¹⁷⁰⁷ Private briefing transcript, Brisbane, 23 January 2019, p 28.

¹⁷⁰⁸ Quality of Care Collaborative Australia, (QuoCCA) Home, <https://www.caresearch.com.au/quocca/>.

directors) with an interest in supporting children with palliative care needs may access this program.¹⁷⁰⁹

Learning options include:

- *Education sessions – scheduled multidisciplinary sessions can be arranged at any metropolitan, regional, rural or even remote setting. Half or full day workshops are available.*
- *Pop- up ... A team of specialist paediatric palliative care teams and educators can visit for education around a specific case consult as guided by the child, family and/or local health team.*
- *Self-paced On-line learning module: Communicating with families about children who have life-limiting conditions.*¹⁷¹⁰

The Paediatric Palliative Care Working Group advised that the QuoCCA model:

...consists of 'just in time' learning via face to face case consultations between the tertiary specialist team and local/community inter professional services.

*Pop-ups may occur for different reasons at the time of diagnosis, deterioration, difficult to manage symptoms or for end-of-life care. The inter-professional team assess for when a pop-up consultation is required, guided by: the patient's clinical need; psychosocial care of the family, education needs of local clinicians, bereavement follow-up and geographical location (rural/remote).*¹⁷¹¹

Online and telephone guidance

The palliAGED website is an 'online evidence-based guidance and knowledge resource about palliative care in aged care for use by health professionals and the aged care workforce'.¹⁷¹²

The End of Life Directions for Aged Care (ELDAC) is a national specialist palliative care and advance care planning advisory service. This service comprises a comprehensive website and a telephone advisory service. According to the ELDAC website:

ELDAC uses innovative technology solutions to assist those who work in aged care and palliative care. The tools will provide access to information and resources including toolkits for those who provide residential aged care, home care and primary care. A telephone and web-based navigation service will help aged care workers, nurses and GPs to find information about end of life care and relevant local or regional services.

*The project is building linkages between healthcare providers in specialist palliative care services and in the aged care sector with the aim of improving the quality of care for people in residential and community aged care settings.*¹⁷¹³

Professor Yates told the committee ELDAC:

¹⁷⁰⁹ Quality of Care Collaborative Australia, Quality of Care Collaborative - Australia: Delivering education in paediatric palliative care, <https://www.caresearch.com.au/caresearch/tabid/3967/Default.aspx>.

¹⁷¹⁰ Quality of Care Collaborative Australia, Quality of Care Collaborative - Australia: Delivering education in paediatric palliative care, <https://www.caresearch.com.au/caresearch/tabid/3967/Default.aspx>.

¹⁷¹¹ Submission 2558, p 7.

¹⁷¹² Palliative Care Aged Care Evidence, About palliAGED, <https://www.palliaged.com.au/tabid/4362/Default.aspx>.

¹⁷¹³ End of Life Directions for Aged Care, About the Project What is ELDAC?, <https://www.eldac.com.au/tabid/4895/Default.aspx>.

*...is about improving end-of-life care for older people in both residential and community care settings. We are now two years into that program. That program has four main streams of work. One is around embedding tools and resources to help aged-care providers, embedding some digital solutions to have access to information and, on the ground, we have employed what we call our partnership facilitators who are working with aged-care providers to see how you can build a link between an aged-care service and a specialist palliative care service to build capability. It is quite an innovative program.*¹⁷¹⁴

Queensland Health

Queensland Health funds the Centre for Palliative Care Research and Education (CPCRE), which is hosted by Metro North Hospital and Health Service at Royal Brisbane and Women's Hospital. Its focus is to 'enhance palliative care education and research throughout the State' by:

- *Developing capacity of the palliative care workforce to provide quality palliative care*
- *Improving links between research and practice in palliative care*
- *Undertaking research to enhance the quality of palliative care*
- *Providing information which supports delivery of palliative care services.*¹⁷¹⁵

Mr John Haberecht, President and the Director of Learning and Development at the Centre for Palliative Care Research and Education, Palliative Care Queensland, told the committee CPCRE provides face-to-face and some online education. Mr Haberecht also advised that CPCRE 'is able to provide tailored education, usually to aged-care facilities. Often it is a challenge to get people to take up that opportunity'.¹⁷¹⁶

17.2 Workforce issues

Broadly speaking, stakeholder views on workforce fell into two areas - workforce shortages and training and development. These are discussed in turn below.

17.2.1 Workforce shortages

A number of inquiry participants referred to considerable staff deficits in the palliative care workforce, across the various professions, with some arguing that dedicated funding and education programs were required to address the shortfall.¹⁷¹⁷

The ACSA commented that 'There are severe shortages of specialist GPs, nurses and allied health staff with specialised palliative care skills, experience and knowledge'.¹⁷¹⁸

Family Voice informed the committee that, compared to other states, Queensland has the third lowest ratio of palliative care doctors per capita:

*The state has 0.9 full-time-equivalent (FTE) palliative care specialists per 100,000 residents, just ahead of WA (0.57), Victoria (0.7), and marginally under New South Wales (1 per 100,000) and South Australia (1.1). Only the Northern Territory and the Australian Capital Territory with 1.9 specialists per 100,000 are near to Palliative Care Australia's benchmark of 2 per 100,000.*¹⁷¹⁹

¹⁷¹⁴ Public hearing transcript, Brisbane, 5 July 2019, p 39.

¹⁷¹⁵ Queensland Health, CPCRE - Centre for Palliative Care Research and Education, <https://www.health.qld.gov.au/cpcre>.

¹⁷¹⁶ Private briefing transcript, Brisbane, 23 January 2019, p 28.

¹⁷¹⁷ See, for example, submissions 1210, 1219, 1252,

¹⁷¹⁸ Submission 1285, p 6.

¹⁷¹⁹ Submission 1248, p 2.

Dr Patricia Lee-Apostle, Palliative Medicine Specialist at the Toowoomba Hospital, provided another example:

*At the moment, we do not have enough workforce. I can tell you that in the workforce alone in the Darling Downs and mapping it through—and this is according to Palliative Care Australia data—the recommendation is that we should have two full-time palliative care specialists for every 100,000 people. For the Darling Downs, we should have 5.56 but what we have at the moment is one. We have clinical nurse consultants. Across the whole of the Darling Downs, there are only three and they are all 0.5. That is spanning such a big geographical area. We should have, with benchmarks, 2.76 so we have a shortfall of 1.26. For community nurses, we have 1.5; we should have 5.5. That is a shortfall of four FTEs. For clinical nurse consultants, we have one; we should have 1.7. That is a shortfall of 0.7. The workforce alone in the specialist area is very understaffed.*¹⁷²⁰

Ms Greenwood from CHA identified nursing workforce shortages as a significant barrier to providing good palliative care.¹⁷²¹

Queensland PHNs provided the following example of the recruitment challenges for palliative care:

*Recruitment challenges for Palliative care in regional Qld results in inequity of in home care services for regional Australians. E.g. After 18 months of recruitment still no Palliative Care Physician for WBHHS [Wide bay Hospital and Health Service], as they only have funding for .5FTE. This is acerbated [sic] by long term Palliative Care Outreach Physician for WB [Wide Bay] and CQ [Central Queensland], Dr Peter Whann [sic] retiring July 2019 with no succession planning or backfill in place.*¹⁷²²

Palliative Care Queensland noted that the limited number of palliative care physicians in some areas of Queensland potentially creates health and wellbeing issues for this group of health professionals. For example, in the Sunshine Coast HHS there is one specialist palliative care physician on 24 hour call every second or third night 365 days of the year.¹⁷²³

Palliative Care Queensland also stated that ‘specialist palliative care clinicians are at high risk of reduced well-being, often related to inconsistent self-care practices’.¹⁷²⁴ Palliative Care Queensland further added, that ‘these feelings can be exacerbated by confrontation with unmet demand for services and the continual need to undertake triage work’.¹⁷²⁵

Similarly, Palliative Care Nurses Queensland referred to the impact of an already under-resourced sector on nurses, stating:

*...nurses currently practising in the highly demanding field of palliative care are caring for people with increasingly complex health needs and are themselves facing the prospect of ‘burnout’, which can leads to workplace injury/illness and overall attrition of the palliative care workforce. This will in turn, lead to poorer care outcomes for palliative care patients and their families. Additionally, there is not only an ageing population, but also an ageing workforce in palliative care.*¹⁷²⁶

¹⁷²⁰ Public hearing transcript, Toowoomba, 17 May 2019, p 8.

¹⁷²¹ Public hearing transcript, Brisbane, 4 July 2019, p 67.

¹⁷²² Submission 1301, p 11.

¹⁷²³ Submission 1891, p 23.

¹⁷²⁴ Submission 1891, p 40.

¹⁷²⁵ Submission 1891, p 40.

¹⁷²⁶ Submission 1305, p 3.

17.2.2 Need for training and development

Unsurprisingly, stakeholders called for greater investment in the training and development of palliative care specialists, as well as training and education for the broader health and aged care workforce, to address the current workforce shortfall as well as to improve the quality of palliative care provision.

Palliative Care Queensland summarised the sentiment of inquiry stakeholders when advocating for the development of the health workforce:

*The need for palliative and end-of-life care has grown significantly over the last 20 years and will continue to grow well into the future. We need to have a whole-of-system approach to palliative care that includes the whole health and social care workforce. Not everybody needs specialist palliative care support. However, specialist services are reporting more and more referrals for care in the last few days. Palliative care is everybody's business and most people should be able to experience quality palliative care anywhere within our health system.*¹⁷²⁷

SVHA stated there is an urgent need to increase training positions and palliative medicine positions across the state to meet future demand, particularly to address the shortfall in regional, rural and remote areas.¹⁷²⁸

Dr Greg Parker, Chair of the QSPCSMDG, emphasised the need for clinical educators, but stated that 'We do not have the ability to workforce develop and create those training platforms.' He also advised that for nurses that can do graduate training programs, 'It is costly, it is time-consuming and it is hard. I do not think that as a structure we support them to get that training'.¹⁷²⁹

In response to a question about whether this means that nursing and allied health service providers are learning on the job, Dr Parker replied 'That is fair to say....We need to invest in a specialist workforce to be able to do that and support that learning environment by creating those training positions'.¹⁷³⁰

Mrs Decima Jones described the difficulties with replacing experienced nursing staff:

*When one of our experienced Palliative Care CNC's leaves or retires, it takes at least 4 months (even with an experienced nurse) to build the critical knowledge base in Palliative Care required for the day to day function of the department. You multiply this over the next 10 years and it begins to paint a grim picture of the difficulties ahead for Palliative Care services as more experienced health professionals leave and the health care needs of the community increase.*¹⁷³¹

Palliative Care Queensland noted that while many clinicians today have some form of palliative care content in their undergraduate education as well as access to various online resources, 'up to 50 per cent of current Australian healthcare clinicians have little or no undergraduate training in end of life or palliative care'.¹⁷³² Dr Richard Corkill, Clinical Director of Palliative Care Services at the Townsville Hospital and Health Service, commented on this statistic, stating 'I think that is a big miss, especially considering we are relying on our generalist colleagues to provide generalist palliative care in the ED, in remote and rural hospitals and in GP clinics. I think we need to address this'.¹⁷³³

Palliative Care Queensland also commented on the role that nurses play in hospital, stating that 'many hospital staff recognise that dying in hospital is not preferred but lack the capacity or understanding

¹⁷²⁷ Public hearing transcript, Brisbane, 4 July 2019, p 82.

¹⁷²⁸ Submission 1280, p 21.

¹⁷²⁹ Public hearing transcript, Brisbane, 5 April 2019, p 10.

¹⁷³⁰ Public hearing transcript, Brisbane, 5 April 2019, p 10.

¹⁷³¹ Submission 1360, p 7.

¹⁷³² Submission 1891, p 40.

¹⁷³³ Public hearing transcript, Townsville, 29 May 2019, p 6.

of community services to arrange transfer of care to the community', further noting that 'this is particularly salient when rapid discharge is required to support imminently dying clients'. Acknowledging the role that nurses have in educating the family, PCQ commented that 'many nurses have limited understanding of palliative care and community care, making this task very challenging to complete'.¹⁷³⁴

As noted in section 12.4.1 of the aged care report, there are barriers to aged care staff receiving training in palliative care. Palliative Care Queensland acknowledged that while information is much easier to access than before through initiatives such as palliAGED, educational barriers in the residential aged care sector remain, and include high staff turnover, time constraints and lack of institutional commitment.¹⁷³⁵ Palliative Care Queensland further advised that for those staff that do participate in training, the capacity to translate that learning into practice is limited.

Mrs Ally Moss, a Clinical Nurse Consultant with CiMaS, told of her experience in trying to educate staff in RACFs to recognise when someone may need palliative care:

*What we have been seeing over the last year is that, as relationships have built with the facilities and GPs, we are getting an increase in referrals. We are often getting referrals for crisis management. By the time we get there the resident is already in crisis. They may be quite symptomatic or they may be actively dying. We have had to think about how we can improve our service and how we can manage the increase in the referrals and try to get the facilities to a good point of being able to either refer or recognise much earlier someone who is at risk of dying without a plan.*¹⁷³⁶

17.3 Suggestions for improvement

As mentioned earlier, funding is inextricably linked to most of the concerns identified with the delivery of palliative care in Queensland. The development of the palliative care workforce is one of those concerns. The imperative to grow, recruit, train and retain staff as necessary is all reliant on appropriate funding. The following sections do not address funding directly, but increased funding would be required to make the improvements recommended by stakeholders.

17.3.1 Addressing workforce shortages

Stakeholders called for modelling of the current workforce to identify gaps in the current workforce, as well as modelling to ascertain future workforce demand to better meet the needs of those requiring palliative care.

The ANZSPM called for the 'implementation of appropriate standardised data collection processes across generalist and specialist services and government/non-government services in order to quantify unmet palliative care needs and service setting preferences'.¹⁷³⁷

Queensland PHNs also submitted that because of rising demand for palliative care staff due to an ageing workforce and shortages of medical and nursing staff trained in palliative care:

*...a robust population and needs-based planning approach is required along with adequate funding and investment to ensure appropriate care models and staff are available to provide quality palliative care where and when it is needed.*¹⁷³⁸

Inquiry participants also called for current known shortfalls to be addressed. ANZSPM called for the Queensland Government to remedy shortages in the specialist palliative care workforce (including in

¹⁷³⁴ Submission 1891, p 38.

¹⁷³⁵ Submission 1891, p 39.

¹⁷³⁶ Public hearing transcript, Ipswich, 9 September 2019, p 2.

¹⁷³⁷ Submission 1252, p 7.

¹⁷³⁸ Submission 1301, p 9.

the specialist medical, nursing and allied health fields).¹⁷³⁹ In particular, PCQ recommended the number of specialist palliative care doctors be increased to 2 per 100,000 population in line with Palliative Care Australia's guidelines.¹⁷⁴⁰

The Paediatric Palliative Care Service also referred to the need to increase staffing for paediatric palliative care, particularly to allow more frequent and regular home visits and telehealth consultations to families.¹⁷⁴¹ Staff identified included specialists in 'Paediatric Palliative Care, Nurse Practitioners, Clinical Nurses or Nurse Navigators, Allied Health Staff, Bereavement Coordinators and Program/Administrative Support'.¹⁷⁴² The Paediatric Palliative Care Service also stated:

*There is a need to increase the specialist workforce in paediatric palliative care by increasing the number of staff funded to work in this area (medical, nursing, allied health, program / administrative and chaplaincy) at the Queensland Children's Hospital. This should be mapped to the Clinical Services Capability Framework (Queensland Health).*¹⁷⁴³

Palliative Care Nurses Australia noted that the current number of FTE nurses will not be adequate to provide quality palliative care for the ageing Queensland population. Due to the specialist skills and abilities of palliative care nurses, Palliative Care Nurses Australia advised that funds need to be committed for workforce staffing, support and development needs.¹⁷⁴⁴

Dr Richard Corkill, Clinical Director of Palliative Care Services at the Townsville Hospital and Health Service, encouraged investment in the palliative care workforce, and in particular increasing the numbers of nurse practitioners who 'can add greatly to the residential aged-care population'. Dr Corkill also advised he 'would like to see more doctors, allied health workers and even volunteers'.¹⁷⁴⁵

The AMA Queensland similarly stated it:

*...recognises the need for and strongly promotes specialised palliative care training and education. Access to this training and education should exist for all providers of palliative care within the medical, nursing and allied health professions, as well as within the community generally. The special training needs of volunteer palliative carers should also be taken into account.*¹⁷⁴⁶

To assist with the implementation of community-based palliative care models, AMA Queensland also suggested that:

*Each major training hospital should be resourced to set up a highly skilled palliative care team within a specialised dedicated Palliative Care Unit. Although hospital-based, these teams should support and work within the framework of the community-based palliative care model.*¹⁷⁴⁷

In addition to the call for an increase in specialist palliative care health workers, stakeholders also identified the need for specialist support for non-specialist health care and aged care staff.

Noting that aged care providers report limited access to palliative care advice and support, and that there are 'severe' shortages of specialist GPs, nurses and allied health staff, ACSA called for support to

¹⁷³⁹ Submission 1252, p 7.

¹⁷⁴⁰ Submission 1891, p 5.

¹⁷⁴¹ Submission 2558, p 2.

¹⁷⁴² Submission 2558, p 3.

¹⁷⁴³ Submission 2558, p 5.

¹⁷⁴⁴ Submission 1305, p 3.

¹⁷⁴⁵ Public hearing transcript, Townsville, 29 May 2019, p 7.

¹⁷⁴⁶ Submission 1233, p 8.

¹⁷⁴⁷ Submission 1233, p 8.

be provided through greater access to 24 hour advice and support for GPs and the aged care workforce to specialised services.¹⁷⁴⁸ ACSA advised the committee:

*Palliative care knowledge and expertise are not consistently embedded into the delivery of care across different health care sectors and professions by health care professionals who do not specialise in palliative care...which means providers need access to palliative care advice and support services.*¹⁷⁴⁹

Avant Mutual referred to disparities in service provision and access in regional, rural and remote areas of Queensland where there are fewer specialised palliative care doctors practising than in the major cities, submitting:

*These communities are often reliant on a small number of general practitioners to deliver a wide range of services. We are concerned that the lack of palliative care specialists in regional, rural and remote areas is a barrier to delivering the best care possible towards the end of life. As the population ages and treatment options become more technically complex and varied, the challenges faced by general practitioners in these areas will only become more difficult unless the government intervenes with appropriate resourcing. Although in some areas there is a need for the provision of support for the appointment of palliative care specialists, where this does not exist general practitioners need to be supported by having specialist resources available for them for consultative support to help them deliver this specialised area of care.*¹⁷⁵⁰

Professor Patsy Yates supported the idea, and similarly told the committee:

*I think it is about the capability of the workforce as well. That does not mean that it is about everyone being a specialist. So long as people have the capability to know where they need to refer on and know where to get that support, we can often deliver good outcomes in a team approach. I think it is about the integration of services. I think it is about the linking of our services. Obviously, to make that work there have to be the appropriate mechanisms, incentives and funding models. It is easy in principle. Everyone says, 'Integrated care,' but it needs the right structures to enable it.*¹⁷⁵¹

Ms Rosie Laidlaw, Acting Director of Nursing at Ipswich Hospice Care Inc, raised the importance of providing palliative care to all with a life-limiting condition, not just cancer patients in metropolitan areas. To achieve this, she suggested:

*A fundamental shift would need to take place about where and who can provide this care in the future. Specialist palliative care provides the expertise to manage complex symptoms and psychological needs. It is a small clinical discipline and will not be able to expand sufficiently in time to provide care for all of those with life-limiting conditions and it is questionable whether this is really necessary. Other jurisdictions have successfully developed generalist community based palliative care models managed by GPs and nurses who have access to the advice of a specialist palliative care expert when required. That could be an alternative model. Hospices can be the key partner in such models, providing respite care to patients when they require it and an alternative to dying at home if their needs are too great for their families to manage or if they have not sufficient social support to remain in their place of residency.*¹⁷⁵²

¹⁷⁴⁸ Submission 1285, p 6

¹⁷⁴⁹ Submission 1285, p 5.

¹⁷⁵⁰ Submission 1238, pp 4-5.

¹⁷⁵¹ Public hearing transcript, Brisbane, 5 July 2019, p 40.

¹⁷⁵² Public hearing transcript, Ipswich, 9 September 2019, p 5.

17.3.2 Addressing training and development needs

Palliative Care Queensland and the QNMU both raised the issue of core competencies to inform training in palliative care. The QNMU supported the development of core competencies for entry level palliative care practice as well as advanced practice.¹⁷⁵³

Palliative Care Queensland referred to five key competencies developed by the Gold Coast HHS for palliative and end-of-life care:

1. *Communicate with compassion*
2. *Recognise the dying trajectory*
3. *Refer, escalate and coordinate care*
4. *Provide supportive care i.e. manage symptoms and promote psychosocial well-being*
5. *Act within legal and ethical frameworks.*¹⁷⁵⁴

In addition to competencies, stakeholders suggested a range of approaches for the training and development of health and aged care staff. Palliative Care Queensland outlined a four tiered approach to address workforce education, based on the setting of care. Palliative Care Queensland submitted that the educational requirements to sustain a workforce that can deliver palliative and end-of-life care to a wide range of Queenslanders living with life-limiting disease requires a focus on the following four sites of palliative and end-of-life care:

- the community (via volunteer training)
- the residential aged care facility (via partnerships with universities and hospices)
- the hospital (via the End-of-Life Care Pathway and the PEPA program), and
- specialist palliative care units/hospices (national and international conferences, short courses, and local activities).¹⁷⁵⁵

While a number of stakeholders suggested training volunteers as a means of addressing the workforce shortfall, PCQ provided the following warning:

*While the use of volunteers in palliative care is advocated, the programs require strong leadership, supervision and educational support. Further, there is limited robust evidence regarding the efficacy and feasibility of these services in combination with specialist and non-specialist palliative care (PCA, 2018b). While volunteers offer a potential workforce, their ability to provide high quality, safe care must be addressed by appropriate education.*¹⁷⁵⁶

A number of stakeholders recommended that all health workers be trained in at least a basic level of palliative care. For example, Dr Will Cairns submitted that:

*One of the core components of an effective palliative care strategy for Queensland is to empower, upskill and incentivise all health workers so that they can provide non-specialist care to their dying patients at a level appropriate to their role. This is particularly true in rural areas where visits from specialist doctors, nurses, counsellors, OTs etc. will always be occasional events.*¹⁷⁵⁷

¹⁷⁵³ Submission 1213, p 29.

¹⁷⁵⁴ Submission 1891, p 38.

¹⁷⁵⁵ Submission 1891, pp 38-40.

¹⁷⁵⁶ Submission 1891, p 38.

¹⁷⁵⁷ Submission 1940, p 17.

Queensland PHNs called for improved palliative care education, support and mentorship for all health professionals, with a particular focus on general practitioners and residential aged care staff.¹⁷⁵⁸

Similar to Queensland PHNs, some stakeholders commented particularly on the importance of training for all staff working in residential aged care facilities. For example, Southern Cross Care stated:

...what is required at a Residential Aged Care facility level is assistance with ongoing staff training and education around palliative care, and symptom management, to ensure quality care is provided.

*Such an approach, if appropriately funded would also lead to reductions in the burden and cost for the community and the State health system.*¹⁷⁵⁹

Anglicare also called for 'greater funding, resources, education and training to upskill staff and volunteers in the aged care sector in end of life and palliative care'.¹⁷⁶⁰

Cancer Council Queensland recommended Queensland Health 'extend educational opportunities and training resources in end-of-life decision making to all caring staff in residential aged care facilities, as part of the implementation of the Statewide strategy for end-of-life care 2015'.¹⁷⁶¹

Palliative Care Queensland also identified two models which may further education in residential aged care settings. The first was the Australian Government's Teaching and Research in Aged Care (TRACs program) which is characterised by a partnership approach between care facilities and universities. Palliative Care Queensland contended that such a model could be developed with partnerships between local hospices and health services, and higher education sector.¹⁷⁶² It also suggested partnership arrangements with hospice services, whereby hospice staff can provide consultancy services, akin to families in home based care. This would provide opportunities for RACF staff to learn by doing, in the same way that families learn about end of life care.¹⁷⁶³

Professor Patsy Yates supported the idea of training across the health and aged care sectors, and suggested a tiered approach be taken:

*One thing that we try and promote about workforce development is that sort of tiered approach. It is understanding that everybody should know something, because you might come into contact with it. That something might be awareness, knowing how to refer or knowing that immediate need. If you are working in a setting where you have a little bit more intensity and complexity, you need a higher level of capability up to a specialist sort of level. We have designed our programs to get the right outcome at the right level as best we can.*¹⁷⁶⁴

ANZSPM also suggested a tiered approach as follows:

- *Mandate training in minimum competencies in end-of-life care management and communication skills for tertiary education and vocational training for all health professionals in Queensland.*
- *Mandate end-of-life care and communication skills workplace competencies and continued professional development to ensure currency of skills for all clinically based health care professionals in Queensland.*

¹⁷⁵⁸ Submission 1301, p 11.

¹⁷⁵⁹ Submission 1245, p 5.

¹⁷⁶⁰ Submission 1253, p 5.

¹⁷⁶¹ Submission 1303, p 8.

¹⁷⁶² Submission 1891, p 39.

¹⁷⁶³ Submission 1891, p 39.

¹⁷⁶⁴ Public hearing transcript, Brisbane, 5 July 2019, p 41.

- *Support clinical educators within Level 6 Palliative Care Services, to facilitate education of the public about the advantages of early referral to palliative care and clinical education of generalist staff delivering palliative care.*¹⁷⁶⁵

Training of clinicians

A number of stakeholders called for clinicians to be provided with at least a basic level of training in palliative and end-of-life care. For example, the RACP emphasised the importance of appropriate training for non-specialists, recognising that all physicians are likely to be involved in the identification and care of patients who are nearing the end of their lives. The Royal Australasian College of Physicians stated:

*Good end of life care must be embedded throughout the health system as not all patients require, or can access, specialist palliative care, and that ongoing funding shortages and variations in health care delivery across Australia make it necessary for non-palliative care clinicians to provide good end of life and palliative care to thousands of patients. Training for all clinicians is thus required to recognise the need for palliative and end of life care, overcome misconceptions around such care and reluctance to refer and to provide appropriate end of life care to all patients in all settings. This is especially crucial as health professionals less comfortable with end-of-life care have been shown to offer patients lower levels of both primary and secondary palliative care.*¹⁷⁶⁶

Southern Cross Care submitted that, based on its experience in a number of rural and regional communities:

*...it is evident that local General Practitioners (GP) would also benefit greatly from an increased focus on palliative care training. This could be supplemented with remote support concerning end of life care and pain management best practice.*¹⁷⁶⁷

Both ANZSPM and academics from the University of Queensland, called for mandated training of all Queensland Health clinicians in basic end of life care ‘to ensure currency of skills for all clinically based health care professionals in Queensland’.¹⁷⁶⁸ ANZSPM also called for communication skills, workplace competencies and continued professional development to be mandated.¹⁷⁶⁹

Dr Richard Corkill, Clinical Director of Palliative Care Services at the Townsville Hospital and Health Service, similarly called for training for all workers involved in palliative care, stating ‘I would love to have training. I think we need to invest in training of all our colleagues involved in palliative care—communication skills as well as the tools we need to look after our patients’.¹⁷⁷⁰

Suggestions were also made by stakeholders that training be provided to certain health workers to assist them with specialising in palliative care.

ACSA recommended that assistance be given to ‘GPs, allied health staff and other specialists to attain specialised skills and knowledge for palliative care’.¹⁷⁷¹

AMA Queensland supported the idea of training a group of general practitioners to take a role in facilitating a greater palliative care participation and commitment of their GP colleagues:

¹⁷⁶⁵ Submission 1252, p 8.

¹⁷⁶⁶ Submission 1203, p 2.

¹⁷⁶⁷ Submission 1245, p 4.

¹⁷⁶⁸ Submission 1252, p 7; submission 1219, p 4.

¹⁷⁶⁹ Submission 1252, p 7.

¹⁷⁷⁰ Public hearing transcript, Townsville, 29 May 2019, p 7.

¹⁷⁷¹ Submission 1285, p 7.

*These practitioners would provide an interface between other General Practitioners, domiciliary nursing and specialised palliative care services, as well as hospitals, nursing homes and other groups involved in professional care. Further, we believe as many GPs as possible should receive sufficient basic palliative care training to enable them to provide high-quality and effective care to palliative patients.*¹⁷⁷²

Introduce palliative care to undergraduate and postgraduate courses

Some inquiry participants suggested that training in palliative care needs to be better integrated into undergraduate and postgraduate courses for health professionals.

Palliative Care Queensland recommended that the Queensland Government ‘Incentivise the inclusion of PCC4U into Queensland undergraduate health professional higher education programs’.¹⁷⁷³

Dr Corkill also spoke in relation to the training of health workers, and GP training in particular, making the following comments:

If we are looking at providing education for GPs, for GP training, that would be another key place. I think we struggle to get GPs to training sessions because they are under time pressure. I reckon we should start right at the beginning, addressing the deficit of the curriculum, because palliative care is not represented enough in the curriculum in medical schools and nursing schools, as far as I am concerned. If we address that, then five or six years later we will have a workforce that understands palliative care. We need to start right from the start: nursing, allied health and medicine. If you guys can put pressure on the medical schools and nursing schools to change the curriculum, I think that would be a big step in the right direction.

I think our target group would be the GP trainees. Dr Robyn Brogan and I are contemplating a breakfast session on a regular basis to bring in palliative care cases and issues with a discussion afterwards. That is one aspect. We provide a study day and a conference kind of workshop for GPs on an annual basis. This year we are going down to Mackay to open the doors there to try to get as many GPs as possible involved in palliative care education.

*I run a program where we have sixth-year medical students come into the palliative care centre. In previous years we had six to eight medical students per year. Over the last three years we have had more than 80 medical students through the doors, seeing how clinicians like Will Cairns can communicate with patients—those sorts of deep and meaningful conversations that Debbie D'urso was talking about—about symptom management or pain management. If we had this replicated throughout Queensland it would make a significant difference in what we are seeing.*¹⁷⁷⁴

Some stakeholders focused on training for nurses in particular. ACSA recommended that increased palliative care education be incorporated in registered nursing formal education programs.¹⁷⁷⁵

Palliative Care Nurses Australia, stated that ‘nursing students and graduates should be exposed to palliative care environments in all settings’ and that ‘education should be embedded as core components of all post graduate nurse programs in Queensland. This should be accompanied by a structured mentoring program’.¹⁷⁷⁶

The QNMU recommended a statewide palliative care workforce plan be developed which incorporates:

¹⁷⁷² Submission 1233, p 8.

¹⁷⁷³ Submission 1891, p 40.

¹⁷⁷⁴ Public hearing transcript, Townsville, 29 May 2019, p 12.

¹⁷⁷⁵ Submission 1285, p 7.

¹⁷⁷⁶ Submission 1305, p 4.

*...investing in recruiting and retaining skilled palliative care nurses... [and] also addresses training pathways including identification of areas of need and support for development of palliative care nurse practitioners at a state level rather than leaving this to the vagaries of HHSs.*¹⁷⁷⁷

Both PCQ and Queensland PHNs called for mentorship programs.¹⁷⁷⁸ Palliative Care Queensland stated:

*Create a mentorship and supervision program led by local specialist palliative care services to support the growth of the palliative care sector and develop local linkages between specialist and generalist services*¹⁷⁷⁹

Queensland PHNs noted the importance of mentorships for GPs and nurses in residential aged care.¹⁷⁸⁰

Stakeholders also called for scholarship and research grant programs. Queensland PHNs recommended that investments in the palliative care workforce include post graduate scholarships and research grants.¹⁷⁸¹

Palliative Care Queensland also suggested that funding be provided for a scholarship program to increase Specialist Palliative Care Nurse Practitioners working in RACFs, as well as palliative care research scholarships 'to ensure the sector has opportunities to lead research and showcase innovations'.¹⁷⁸² Palliative Care Queensland also recommended that grants and scholarships for palliative care and end-of-life care be available for all specialist palliative care and palliative care service providers, not just Queensland Health Service providers. Finally, PCQ recommended that the capacity for tertiary level health services to extend their new graduate nurse programs to include nurses in local residential aged care be explored.¹⁷⁸³

In terms of the education programs, PCQ recommended that the Queensland Government encourage the Commonwealth Department of Health to increase the number of PEPA placements on offer in Queensland by 20% and continue funding for the Centre for Palliative Care Research and Education to support sustainable and consistent education in palliative care.¹⁷⁸⁴

Committee comment

The palliative care workforce

Evidence provided to the committee demonstrates that there are severe workforce shortages in palliative care, and it's likely to get worse due to the ageing workforce and growing demand for palliative care. Measures need to be taken immediately and over the long term to address this staffing shortfall.

The committee agrees with the findings of the Palliative Care Service review that the availability of an accessible, specialist and sustainable palliative care workforce is a critical component of delivering quality palliative care services. The need for such a workforce was widely reflected in the evidence provided during the inquiry. What is less clear, is how the Queensland Government intends to do this.

While the committee acknowledges that there are a number of Queensland Health workforce strategies in place, the committee believes that a palliative care workforce strategy, aligned with the

¹⁷⁷⁷ Submission 1213, p 29.

¹⁷⁷⁸ Submission 1891, p 40; submission 1301, p 11.

¹⁷⁷⁹ Submission 1891, p 40.

¹⁷⁸⁰ Submission 1301, p 11.

¹⁷⁸¹ Submission 1301, p 10.

¹⁷⁸² Submission 1891, p 40.

¹⁷⁸³ Submission 1891, pp 5, 6, 40.

¹⁷⁸⁴ Submission 1891, p 40.

national strategy, and that is based on workforce and population-based modelling, is needed if the Queensland Government is going to develop the necessary workforce.

The strategy will need to remedy shortages in the specialist palliative care workforce (including in the specialist medical, nursing and allied health fields), both to help deliver palliative care services, as well as support other health workers in providing palliative care.

The strategy should also consider the barriers that medical, nursing and allied health staff experience in taking up existing professional development and training as well as further tertiary education, and develop training pathways for those workers. The Queensland Government should consider improving support strategies for current palliative care staff to address issues of fatigue and isolation.

Currently there is a heavy reliance on palliative care specialists, most of whom are based in South East Queensland in the public hospital system. However, it will be important to develop a workforce that can provide palliative care outside of the hospital system — at home, in residential aged care facilities and in the community. This is particularly important to help reduce or avoid inappropriate or unnecessary emergency department presentations, and support people to remain in their home, if that is their preference.

To achieve greater flexibility in the provision of palliative care, when and where a person requires such care, investment will need to be made in the training and development of all staff who may be involved in providing palliative care, including non-specialists. Currently, there appears to be a gap in the training of doctors, nurses, other health staff and personal care workers in recognising and supporting a person's palliative care needs.

Specialist support for care staff who aren't specialists, such as general practitioner, nurses and residential aged care facility workers is key to ensuring good palliative care is provided to the community.

The committee also agrees with the recommendation that a tiered approach to training and development be taken for all health and aged care workers, particularly non-specialists who are likely to still be involved in providing palliative care, such as residential aged care facility workers, general practitioners, nurses and allied health workers in regional, rural and remote areas.

The committee has already recommended that priority funding be allocated to establish a centralised 24-hour, seven day telehealth service to support practitioners throughout the state. Again, this will be particularly important for regional, rural and remote areas.

Of course, funding will be key to workforce staffing, support and development needs. Workforce attraction and retention strategies will also play an important part of any workforce strategy. The recruitment and development of nurse practitioners will play an important part of developing the workforce.

The committee commends the programs that have been developed to provide training and resources in palliative care, and the committee believes these should continue to be funded. However, the Australian and Queensland governments also need to work with tertiary providers and aged care training providers to encourage them to incorporate palliative care into their courses and training, such as through Palliative Care Curriculum for Undergraduates (PCC4U).

Recommendation 59 Develop a palliative care workforce strategy

The committee recommends that the Queensland Government, in conjunction with the peak bodies and unions representing the palliative care workers, model current and future workforce needs and develop a palliative care workforce strategy that aligns with the national strategy and that it includes strategies for:

- increasing the number of palliative care specialists, nurse practitioners, and palliative care nurses via specialised palliative care training and education
- professional development training for all providers of palliative care within the medical, nursing and allied health professions
- educating health workers who may need to provide palliative care as part of their normal health care delivery, for example, general practitioners, nurses and residential aged care facility workers, so they have a basic understanding of palliative care
- recruiting and retaining palliative care staff, and
- addressing issues of fatigue and isolation amongst palliative care staff.

Recommendation 60 Develop specialist support services

The committee recommends that the Australian and Queensland governments develop specialist support services to assist general practitioners, nurses, allied health workers and the aged care workforce, including ways to integrate services to provide support to care workers, such as through mentoring.

Recommendation 61 Incorporate palliative care into tertiary education and training

The committee recommends that the Australian and Queensland governments work to identify strategies to incorporate palliative care training into tertiary courses for medical, nursing and allied health staff, including through Palliative Care Curriculum for Undergraduates (PCC4U), and aged care training providers.

Recommendation 62 Mandatory basic training for personal care workers

The committee recommends that basic palliative care training be made mandatory for personal care workers in residential aged care facilities.

Recommendation 63 Continue funding for professional development programs

The committee recommends that the Australian and Queensland governments continue financial and other support for professional development programs, such as Program of Experience in the Palliative Approach (PEPA) and Centre for Palliative Care Research and Education (CPCRE).

Recommendation 64 Nurses in palliative care

The committee recommends that the Queensland Government explore opportunities to better utilise nurses, nurse navigators and nurse practitioners in the Queensland palliative care system to assist and provide palliative and end-of-life care.

18 Supporting informal carers

Caring for a person at end of life at home often involves a significant commitment by spouses, children, parents and friends. Informal care may precede, take the place of, or complement formal care provided by government or non-government agencies.¹⁷⁸⁵

The Council on the Ageing Queensland recognises that ‘the aged care system is maintained by vast numbers of informal and unpaid carers who provide the majority of care received by older Queenslanders’.¹⁷⁸⁶ Palliative Care Queensland stated that ‘evidence suggests that supporting family caregivers at home, with health professionals specifically trained in end of life care is paramount to enabling a person to die at home’.¹⁷⁸⁷

Submitters considered the number of hours per week of nursing services funded by the Australian Government’s Commonwealth Home Support program to be inadequate because families may have to pay the shortfall in additional hours,¹⁷⁸⁸ or take time from their current employment and other responsibilities to care for their relative.

With an increasing number of people wanting to die at home, additional pressure is being put on the need for informal carers. The Grattan Institute noted in its submission that ‘In 2010, informal carers provided 1.3 billion hours of home care. If paid carers were to do this work it would be worth an estimated \$40.9 billion’.¹⁷⁸⁹

Queensland Health advised that it provides financial assistance to Carers Queensland. According to the department, the Queensland Government funded Carers Queensland \$1.6 million which was renewed for the 2019-20 period.¹⁷⁹⁰

18.1 Challenges faced by carers

Carers face a range of challenges. These challenges were raised in submissions and evidence provided to the inquiry, and included health, social, emotional, economic and employment disadvantages. Cittamani Hospice Service told the committee:

*For people caring for someone at home—the carers—there is a huge burden involved in providing care for that person—a physical and emotional burden that people are willing to take on, and gladly take on.*¹⁷⁹¹

During its inquiry, the committee heard a number of testimonies from carers, outlining their experience and the impact it had on them.

Ms Raelene Ellis attested to the exhaustive nature of caring for a loved one:

*Being an informal carer is really hard. Emotionally, physically, mentally, it’s hard. ... What I needed was more time to do other stuff in my life, because caring for mum meant I was time poor and often feeling depleted and exhausted. It also meant that I had less time to be with my family.*¹⁷⁹²

¹⁷⁸⁵ Department of Communities, Disability Services and Seniors, *About Carers*, <https://www.communities.qld.gov.au/community/carers/about-carers>.

¹⁷⁸⁶ Submission no. 1304, p 4.

¹⁷⁸⁷ Submission no. 1891, Palliative Care Queensland, p 23.

¹⁷⁸⁸ Submission no. 1891, Palliative Care Queensland, p 25.

¹⁷⁸⁹ Submission 24, p 19; Dying Well report, p 16.

¹⁷⁹⁰ Queensland Health correspondence dated 14 October 2019, p 47.

¹⁷⁹¹ Mr Alex Moore, Cittamani Hospice Service, public hearing transcript, Caloundra, 3 May 2019, p 8.

¹⁷⁹² Submission 922, p 18.

...

*We just need more support somehow ie. Not money, but solutions to the exhaustion that comes from caring for a loved one.*¹⁷⁹³

Miss Kim-Maree Burton who appeared before the committee in Mount Isa, outlined her experience as a carer. Ms Burton stated that caring:

*...is an area that is forgotten about with health professionals. It is forgotten about when looking at the financials of health care. It is forgotten about because carers can and often do go on to have their own health issues.*¹⁷⁹⁴

Ms Burton outlined her experience caring for her mother with dementia, noting the lack of financial support which was available:

*When I was looking after my mother, the carer's payment at that stage equated to 11 cents per hour. In order to attain that carer's payment, which I could not because I was self-employed at that stage, the rigmarole that I had to go through was astronomical, and that was to save the government money. You kept your loved one at home at your own expense. I mean not only financially but also personally in terms of your own health and your own career. I ended up having to give up my career as such and look after my mother.*¹⁷⁹⁵

Ms Burton also acknowledged informal systems of support were lacking, and ultimately resulted in a breakdown:

When you use the word 'dementia' people automatically disappear, and that includes family and friends, because they do not want to be reminded of what mum and dad—or whomever it is—is like today; they want to remember them as they were before. The carer finds that he or she is left to look after themselves; very few people come in... What happened with me has happened to many other people. Some 12 months down the track I had a breakdown, and that was because there was a lack of infrastructure to look after the carers. I have heard people talk today about counselling and going and doing different things. That is not always available and it is also very selective.

....

*If somebody does not look after the carers, they cannot in turn look after their own people.*¹⁷⁹⁶

Ms Erika Gerdson told the committee about caring for her 84 year old father-in-law for seven months prior to his death. Ms Gerdson tabled an eight page document outlining the various entities she dealt with over that time.¹⁷⁹⁷

I gave up my three-day-a-week job, my weekly personal training and yoga sessions as well as my social life, including Facebook. I focused on providing my father-in-law with the best in-home experience any average person could hope for. Without these elements—the money and the family support—he would have most definitely experienced seven miserable months in a nursing home. At home he got the food he wanted, he got the attention he needed and he was consulted on all matters. We even brought in farm animals to his bed, because he was no longer keen to go outside—small farm animals, I should add.

¹⁷⁹³ Submission 922, p 20.

¹⁷⁹⁴ Public hearing transcript, Mount Isa, 31 May 2019, p 20.

¹⁷⁹⁵ Public hearing transcript, Mount Isa, 31 May 2019, pp 19-21.

¹⁷⁹⁶ Public hearing transcript, Mount Isa, 31 May 2019, pp 19-21.

¹⁷⁹⁷ Erika Gerdson, *My Journey with Aged care, end-of-life and palliative care and death on behalf of my father-in-law, August 2018- March 2019*, Tabled Paper, 5 July 2019.

When he had his final stroke and entered into a vegetative state just before lunch one day, we entered another unknown area around palliative care at home. This was also quite a shemozzle and a very distressing and upsetting time.

If you are feeling dizzy looking at that table that I have provided, just imagine you are in your 70s, you do not use email or internet very well—if at all—you have health problems of your own, you do not have any children nearby and you are receiving only a basic pension. How do you think you would manage as a carer or partner for someone after they have had a debilitating stroke?

*In closing, I would like to thank Centrelink for the \$225 per fortnight I received for the 70-plus hours per week of high-quality care that I provided to just one disabled and elderly man. No wonder it is so much cheaper for the government if people are cared for at home.*¹⁷⁹⁸

Mr Colin Horton appeared before the committee in Mossman and described his personal experiences caring for a friend with terminal cancer. Mr Horton and his wife cared for Mr Roy Pratt at their bed and breakfast, even though they had no formal training:

*It was just my wife and me. Fortunately Roy was, by that time, about as big as your little finger and he weighed nothing. When you get to the blood and faeces stage, you have to change nappies and all of that sort of thing. Both of us were doing the very best we could, and I think we did all right.*¹⁷⁹⁹

Mr Horton noted the importance of informal carers and those who volunteer to care for people in their community:

The government is never going to be able to pay for the sort of care we gave him, because we are volunteers and because he was a friend. The government is never going to be able to supersede what volunteers can do for people... It is not money that is needed. You hear much talk about people being left alone and nobody doing anything. Where is the family? Where are the friends? Where are the volunteers who are acquiring a sort of karma, because, give it 10 years, five years or six months, that is going to be you in that bed with some total stranger changing your nappy? There should be much more incentive for volunteers, because you simply are not going to be able to afford it, are you?

...

*You will never have the money for it, yet compared to what you spend on a child in day care—you hear figures of \$120 a day for a child—you are not spending anything or maybe half that on somebody and you are paying starvation wages to somebody to be a carer... You are not going to get somebody for whom the job suits by paying starvation wages, because if they are an intelligent, caring person they can earn a damn sight more money somewhere else.*¹⁸⁰⁰

Mr Andrew Stafford told the committee about the care and support he was continuing to provide to his mother as she suffered from early onset dementia. Mr Stafford said, 'Her psychological suffering has been immense, and as her sons and carers we have suffered with her'.¹⁸⁰¹

Submissions to the inquiry indicated that carers are at risk of mental health problems, confront financial issues, need better workplace support, and would be better supported through the adoption of case management approaches with improved coordination.

¹⁷⁹⁸ Public hearing transcript, Brisbane, 5 July 2019, p 51.

¹⁷⁹⁹ Public hearing transcript, Mossman, 28 May 2019, p 12.

¹⁸⁰⁰ Public hearing transcript, Mossman, 28 May 2019, p 12.

¹⁸⁰¹ Public hearing transcript, Brisbane, 13 September 2019, p 67.

In particular, Carers Queensland noted that carers providing end of life care have repeatedly voiced concerns about:

- *unmet needs for information and enhanced communication*
- *more flexible and responsive service provision*
- *uncertainty about the treatments offered*
- *fear about the availability and delivery of culturally safe services*
- *changing roles within the family*
- *lack of affordable and regular transport*
- *strained financial resources*
- *lack of social support and fear of the future.*¹⁸⁰²

The Grattan Institute noted that carers face ‘considerable waiting periods’ to get support through carer packages and home-based care, and stated that ‘without the development of new support for informal care, it is unlikely to be available to meet additional demand’.¹⁸⁰³

ANZSPM believe support and empowerment for informal caregivers as critical, and this should also include the bereavement period.

*Informal caregivers play a significant role in the support and delivery of care for people with life illness, and there are significant gaps in the practical, financial and emotional support available.*¹⁸⁰⁴

In a joint submission, HCQ, PCQ, COTA and Carers Qld Australia summarised:

*The role of carers in providing end-of-life care in the home is crucial. Carers require more support, education and engagement with health professionals, services and supports if they are to meet patient preferences for place of death. Improved quality of planning, communication and education for carers for end-of-life care may assist more people to die at home.*¹⁸⁰⁵

Carers of children requiring palliative care have particular needs and there are additional impacts on siblings and the rest of the family. There are also challenges facing Indigenous communities during a family members’ palliative care treatment. For further discussion of the challenges of providing palliative care for children and providing palliative care in Indigenous communities see section 15.3.

18.2 Improving support for carers

During its inquiry, submitters called for improvements to the available support for informal caregivers. Stakeholders outlined a need for improved access to respite care, access to information and services, and more education and engagement with health service professionals.

Carers Queensland made a number of recommendations including:

- development of a state-based response to respite¹⁸⁰⁶
- palliative care service providers be encouraged and supported to refer carers to their local Carers Queensland office to access specialist support services including counselling to address

¹⁸⁰² Submission 1892, p 3.

¹⁸⁰³ Submission 24, p 20.

¹⁸⁰⁴ Submission 1252, pp 6, 12.

¹⁸⁰⁵ Submission 1892, p 7.

¹⁸⁰⁶ Submission 1892, p 10.

their anxieties and fears, and carer mentoring to help build resilience and create social connection with other carers¹⁸⁰⁷

- support and funding for Palliative Care Queensland's program to establish compassionate communities throughout Queensland, which would act as an advocate, navigator and awareness raiser for community initiatives in this space.¹⁸⁰⁸

A significant issue for informal caregivers is access to timely and appropriate information and support. The information needs of carers requires adequate resourcing and must be responsive to carer and community diversity.

CentacareCQ agreed on the need for support that 'enables new users to navigate and understand their choices in aged care, including family/informal carers'.¹⁸⁰⁹

Council on the Ageing (COTA) Queensland believe that service providers and health professionals should acknowledge and respect a person's informal support system and ensure 'user-friendly information and good communications at all times'.¹⁸¹⁰

18.2.1 Access to respite care for carers

As highlighted in the WHO definition, the aim of palliative care is not only to care for people with life-limiting or terminal conditions but also to provide practical and emotional support to family and carers. This approach to supporting families is also part of a person-centred model of care. Respite is a vital element of support for carers.¹⁸¹¹

Carers Australia conducted a survey of Commonwealth Respite and Carelink Centres and similar providers to investigate reports from carers and other stakeholders that respite in residential aged care facilities is becoming increasingly difficult to access.¹⁸¹² The survey results reported high demand for residential respite care, difficulties in accessing respite and a lack of respite beds, particularly for people with high care needs, including dementia.¹⁸¹³ The survey also found that 'where services are often only available in two-week blocks or longer, there is a high demand for, and a low supply of, overnight and weekend respite in more informal settings, such as respite cottages'.¹⁸¹⁴

The issue with access to respite for carers was raised by a number of stakeholders during the inquiry, who advocated for increased resourcing and availability of respite.

The importance of respite services being accessible for carers was noted by the PCQ:

*For a number of these people because they are elderly, you have an elderly carer looking after a dying person. Who is supporting the elderly carer who is up two or three times at night because their loved one needs turning or they are wet or they are not sleeping? They are restless, so the carer is not getting any rest. Who is helping them? That is where the community has to come in and help that family.*¹⁸¹⁵

The Australian Association of Social Workers also highlighted the need for respite for carers. In particular, it suggested:

¹⁸⁰⁷ Submission 1892, p 13.

¹⁸⁰⁸ Submission 1892, p 13.

¹⁸⁰⁹ Submission no. 1297, p 7.

¹⁸¹⁰ Submission no. 1304, p 4.

¹⁸¹¹ See, for example, submissions 1892, p 10; 1243, p 9; E10, p 50; 920, p 21.

¹⁸¹² Submission 1892, p 10.

¹⁸¹³ Submission 1892, p 10.

¹⁸¹⁴ Submission 1892, p 10.

¹⁸¹⁵ Ms Karen Gower, State Council Member, PCQ, (In camera) transcript, 23 January 2020, p 25.

*There is also a need for more short-term in-home overnight carer respite. Currently, people can only access longer-term residential respite, limited cottage respite or emergency respite care which do not necessarily meet the needs of all people and their carers.*¹⁸¹⁶

Aged and Disability Advocacy Australia similarly recognised the need for increased access to overnight in-home respite and residential respite:

*These services are essential in supporting family members/ friends and representatives in their informal care giving roles. ADA Australia's advocates do report a shortage of locally available residential respite options. In rural and remote areas residential respite services are limited. In regional and metropolitan areas, the locally based residential respite services are often at capacity and managing extensive waiting lists. The shortage of local options can result in consumers having to travel significant distances to access appropriate respite ... The barrier of distance can result in the older person experiencing stress, anxiety and disorientation associated with being removed from their home and local community. It can also impact on the ability of the carer, friends and family to visit the older person during their respite stay, causing feelings of isolation for the respite residents and stress for the carers who sometimes seek peace of mind by visiting their loved ones during their respite stay.*¹⁸¹⁷

Ms Raelene Ellis who submitted to the inquiry as well as the Royal Commission into Aged Care Quality and Safety, provided her mother with care and assistance. Ms Ellis outlined the importance of having respite services available, and noted the current inflexibility of respite services:

*On the topic of caring for informal (unpaid) carers, I think a fantastic change to the respite system would be to be able to have a few days of intermittent respite... As an example of my experience, we went away for a week and I was unable to find any facilities that would take mum for less than a 2 week booking. There should be more ability to do whatever time you want, including just 2 nights so carers can have a break, or even a regular shared care one week on and off, so as to maintain family connections.*¹⁸¹⁸

Committee comment

The committee recognises the extraordinary commitment of partners, other family members, friends, neighbours and others who provide informal care for the dying. It acknowledges the physical, emotional, and financial burden of caring for a loved one at home and after their loved one has passed. The complexities involved in the delivery of services to patients at home places an additional burden on informal carers.

Providing practical and emotional support, including the provision of professional and financial support, and adequate access to respite services is imperative for informal carers, and enables people to die at home rather than in a hospital or aged care environment. Inquiry stakeholders reported that carers needed access to timely information and support which often came after a considerable waiting period. The committee acknowledges the important work of Carers Queensland, with financial support provided by the Queensland Government, in delivering self-help and self-care for carers through appropriate support, information, education and training.

The evidence presented to the committee indicates that the paucity of respite care for periods of less than two weeks is impacting on informal carers personally and on their capacity to care for their loved ones at home. Lack of respite care should be addressed as a matter of urgency.

The committee recommends that the Australian Government look at ways to increase the availability of respite care available to carers.

¹⁸¹⁶ Submission 1288, p 19.

¹⁸¹⁷ Submission 1243, p 9.

¹⁸¹⁸ Submission 922, p 27.

Recommendation 65 Respite care for informal carers

The committee recommends that the Australian Government improve the availability of respite services for informal carers providing end-of-life care to the dying, and provide for more flexible delivery to allow for short-term respite.

19 Public Awareness and Community Involvement - Palliative Care

Inquiry participants called for increased public awareness about palliative care and end-of-life care.¹⁸¹⁹ Submitters told the committee that increased awareness was necessary to break down the barriers caused by societal taboos around the discussion of death and dying and to increase the community's understanding of the role of palliative care and where to find services. They also commented on the benefits that would flow from increased community awareness of palliative care and the importance of building compassionate communities. Stakeholders discussed current initiatives to increase public understanding of death and dying and the role of palliative care and to build community involvement. Submitters proposed future initiatives to raise awareness and initiatives to activate community involvement.

19.1 Public awareness of palliative care

The importance of public awareness of palliative care is reflected in the first goal of the National Palliative Care Strategy 2018, Understanding, which states: '[p]eople understand the benefits of palliative care, know where and how to access services, and are involved in decisions about their own care'.¹⁸²⁰

Inquiry participants also stressed the importance of public awareness of palliative care, including Mr Daniel Prentice, Professional Research Officer, QNMU:

*Raising public awareness is something that is very important. I think attitudes towards dying and the care of those who are on that trajectory is very important. I think we referred earlier to advance health directives again as a way of raising awareness. We would be very supportive of any initiatives to do that within the broader community. It is very important to have the community on board when we are talking about issues particularly like end-of-life care and that much shorter period which we would constitute as palliative care at the end of that period.*¹⁸²¹

In its Palliative Care Services Review, Queensland Health found there was a need for increased information and awareness:

*The evidence, research and analysis support the finding from the Review that there is an ongoing need to provide comprehensive and timely information about palliative care services for individuals, families and carers throughout their palliative care journeys. There is also a demonstrated need to increase awareness of, and education about, palliative care services among the general community and health professionals that are not directly involved in the delivery of these services.*¹⁸²²

19.1.1 Why raise awareness of palliative care?

The committee heard it is important to increase awareness of palliative care to overcome a reticence to talk about death and misunderstanding of the role of palliative care, both of which act as barriers to palliative care and end-of-life care.

Submitters informed the committee that access to palliative care and end-of-life planning was hindered by societal taboos around discussing death. The Grattan Institute stated that the 'failure to talk about and plan for death is one of the most significant obstacles to improving the quality of dying'.¹⁸²³ They also explained:

¹⁸¹⁹ For example, QNMU, submission 1213, p 29; PCQ, submission 1891, p 3; Catholic Health Australia, submission 1249, p 6; ANZSPM, submission 1252, p 7.

¹⁸²⁰ Australian Government, Department of Health, *National Palliative Care Strategy 2018*.

¹⁸²¹ Public hearing transcript, 4 July 2019, Brisbane, p 23.

¹⁸²² Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 38.

¹⁸²³ Submission 24, p 14.

*As a community, we struggle to talk about death. We prefer euphemisms – “passed on” and “resting in peace” -- to direct speech. We focus more on hopes for the next medical breakthrough than on the limits of health care when death is near. Public discussion of death may even be more cloaked than it was for earlier generations, when death was more common. Preparation for death has become technical, private and hidden.*¹⁸²⁴

This echoed the finding of the evaluation of the *National Palliative Care Strategy 2010*, which found that ‘The need for public awareness and understanding of the process of death and dying continues to be identified as a barrier for managing pain and symptoms for many people at the end of life’.¹⁸²⁵

The importance of community awareness to overcome the difficulty of talking about death was also discussed in the *National Palliative Care Strategy 2018*, which states that ‘raising awareness and helping people understand the importance of palliative care is necessary to ensure that they can talk about their wishes for the end of life’.¹⁸²⁶

In its submission, AMA Queensland recommended that ‘[t]o address the cultural and societal taboos with regards to discussion and acceptance around death and dying, the Queensland Government must invest in a public education campaign to improve community literacy and knowledge about the issue’.¹⁸²⁷

One retired medical practitioner recommended to the committee that ‘[f]or improved end of life care involving wider family and their health practitioners, the current society culture “taboo” about death needs to be modified by compulsory and uniform community education started from our teenage high school years’.¹⁸²⁸

Amy Whelan, a community aged care and palliative care clinical nurse who has worked with the elderly and palliative demographic in their homes for the past seven years, submitted that palliative care also was a taboo subject:

*This area of health, being quite a taboo subject as it is not "pleasant" to talk about is quite often one of the lowest priorities on the health agenda. One thing that is for certain, short of a quick and unexpected death, the majority of us and our loved ones will be referred to palliative care at some point in our lives.*¹⁸²⁹

The *Queensland Health Palliative Care Services Review – Key Findings* lists lack of awareness of, and information about, palliative care services as a barrier to providing good, high-quality palliative care services.¹⁸³⁰ Catholic Health Australia agreed:

Widespread misperceptions and lack of understanding of PC act as a barrier to access. PC is thought by many to encompass pain relief, pain relief with the meaning to hasten death and to be a place where you go to die (Allingham S et al, 2018). This understanding is not limited to health care consumers, but also an understanding held by many health care professionals and represents a significant barrier to accessing PC services (Weil J et al, 2015). Many health

¹⁸²⁴ Submission 24, p 14.

¹⁸²⁵ Urbis, *Evaluation of the National Palliative Care Strategy 2010 Final Report*, p 2.
<https://www.health.gov.au/sites/default/files/evaluation-of-the-national-palliative-care-strategy-2010.pdf>.

¹⁸²⁶ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, p 12.

¹⁸²⁷ Submission 1233, p 7.

¹⁸²⁸ Submission 2100, p 4.

¹⁸²⁹ Submission E1582.

¹⁸³⁰ Queensland Health, *Queensland Health Palliative Care Services Review – Key Findings*, March 2019, p 31.

*professionals and the community retain a view of PC as terminal care, which is appropriate only after disease-modifying treatment has ceased (Johnson C et al, 2011).*¹⁸³¹

Dr Patricia Lee-Apostle, Palliative Medicine Specialist, Toowoomba Hospital, explained to the committee why awareness needed to be increased of the benefits of palliative care:

...we do not have very developed health literacy regarding death and dying. When it comes to palliative care, many people equate that with us getting involved only when people are actively dying—in the last days or the last couple of weeks in life. That is actually not what palliative care is about. There are a lot of trials and studies that show that early palliative care involvement has a lot of benefits in terms of symptom management, in terms of psychosocial and psychological wellbeing of patients and carers, as well as being able to advocate for patients and having those wishes at the end of life be completed in terms of where you want to die or in terms of who are the people that make the decisions. Also it has been proved that early palliative care referral in certain diseases can actually prolong life. There is a survival benefit.

*It is not uncommon when I see people for the first time that they get extremely frightened. They get distressed because they have been referred to palliative care.*¹⁸³²

19.1.2 Benefits of increased awareness of palliative care

A number of inquiry stakeholders shared their perspectives on the benefits that can accrue from increased public awareness of the role of palliative care.

19.1.2.1 Awareness drives community expectations of service delivery

The QNMU advised the committee that '[a]n essential part of supporting and informing community expectations around palliative and end-of-life care relates to increasing awareness and understanding at the community level.¹⁸³³ The QNMU submission to the inquiry stated that '[t]he QNMU believes the development of an informed and engaged community to drive expectations of service delivery must be an essential component of any state wide palliative and end-of-life care strategy'.¹⁸³⁴

19.1.2.2 Awareness may reduce misconceptions and fears

The Australian and New Zealand Society of Palliative Medicine (ANZSPM) recommended the systematic and consistent promotion of community awareness of end-of-life care and palliative care 'to improve health literacy and understanding, and enculturate dying as a normal part of living'.¹⁸³⁵ ANZSMP stated that this would 'hopefully reduce misconceptions and fears around dying and suffering at the end-of life as well as fear of opioids, and lack of awareness of the extent of choice and engagement [sic] possible decision-making in end-of-life care'.¹⁸³⁶

Dr Carol Douglas, representing the Australian and New Zealand Society of Palliative Medicine, elaborated on this benefit:

[a] person may be hindered in seeking palliative services due to their misunderstanding or fear or that of the family about what palliative care is. The analogy would be having a heart attack and not being offered evidence based options of a coronary artery bypass or primary angioplasty as either there was not a clinician with skills to do the procedures or no-one referred you to discuss these options. Our recommendations that specifically address these deficits are: firstly,

¹⁸³¹ Submission 1249, p 5.

¹⁸³² Public hearing transcript, 17 May 2019, Toowoomba, p 7.

¹⁸³³ Submission 1213, p 31.

¹⁸³⁴ Submission 1213, p 31.

¹⁸³⁵ Submission 1252, p 7.

¹⁸³⁶ Submission 1252, p 7.

*community awareness is critical to address misconceptions and fears about dying and also facilitates better awareness of the extent of choice and engagement possible in decision-making at the end of life.*¹⁸³⁷

19.1.2.3 Awareness may result in better patient outcomes

Catholic Health Australia was of the view that increased awareness of palliative care in Queensland may result in better patient outcomes:

*There remains a significant and persistent stigma associated with death and dying amongst health care professionals and in the Australia population in general. Low levels of awareness limits quality and access to care through late referral to PC services, poor symptom control, lack of use of Advance Care Planning (ACP), distress and loss of time to form acceptance (Sellars M et al, 2015). Currently in Australia, 'almost two-thirds of terminally ill people for whom home or hospice palliative care would be appropriate die in hospital, often receiving heroic interventions' that are frequently distressing and unnecessary (Australian Government Productivity Commission, 2017). Initiatives aimed at increasing awareness of PC in QLD have the potential to improve early referrals and engagement with PC services, and ultimately patient outcomes.*¹⁸³⁸

19.1.2.4 Awareness would increase knowledge of available services

The National Palliative Care Strategy 2018 states that 'raising awareness of the services available should help individuals, their families and carers to seek and find the support they need to live well till the end of life, and in bereavement'.¹⁸³⁹

The need for increased awareness of available palliative care services was also highlighted when a long-term nurse and now Pastoral Care Practitioner shared her experience at the time of her mother's death:

*Having been raised in a rural environment, I was at a loss when my mother was dying, on how or where to access assistance for her to die at home, things like beds, comfort measures, emotional support. More education, training and support needs to be provided to community nurses (who are very good) to enable them to converse with families around the process of dying and of the entire journey.*¹⁸⁴⁰

Ms Georgia Cummings, a retired palliative care nurse, explained that although a great deal of information exists about available services, awareness of how to find that information is low:

*Although there is a wealth of information about palliative care and all sorts of tools and training for aged-care nurses and certificate III workers, people do not realise how much is already available that they can access. For example, for me in South Brisbane, I can go onto the website for Queensland Health and I can find out what services are available close to where I live. Helping people to understand how to find the information would be good.*¹⁸⁴¹

19.1.3 **Current initiatives to increase understanding of death and dying and the role of palliative care**

The committee heard of current campaigns to increase awareness of palliative care and to improve the community's understanding of dying and end-of-life options.

¹⁸³⁷ Public hearing transcript, Brisbane, 13 September 2019, p. 38.

¹⁸³⁸ Submission 1249, p 6.

¹⁸³⁹ Australian Government, Department of Health, *National Palliative Care Strategy 2018*, p 12.

¹⁸⁴⁰ Submission 2129, p 2.

¹⁸⁴¹ Public hearing transcript, Brisbane, 4 July 2019, pp 88-89.

Director-General of Queensland Health, Dr John Wakefield, explained to the committee some of Queensland Health's initiatives to increase understanding and knowledge of palliative care and end-of-life care, including the *Care at the end of life* campaign:

*The department funds Metro South to lead on behalf of the state what is called the Office of Advance Care Planning, which incorporates palliative care. That has a significant public-facing website with significant materials. Through the end-of-life strategy ... [t]here is a range of strategies that we have committed to and our government has committed to around informing and upskilling the community and practitioners. There is a website with lots of resource material on it, apps, guidelines, information for consumers and service information. In addition to that we have engaged in some community awareness raising. Last year there were public ad campaigns—and you may have seen those—around kitchen table discussions and starting to talk about death and planning for loved ones and so on.*¹⁸⁴²

The *Care at the end of life* campaign aims to raise awareness about the importance of discussing and planning for care at the end of life. The campaign features videos of clinicians speaking from a professional and personal point of view with the aim of assisting Queenslanders with 'building a shared vocabulary about the topic, normalising discussion around death and dying and motivating people to plan their care at the end of life'.¹⁸⁴³ This campaign was Australia's first government-led statewide public awareness campaign on care at the end of life and advance planning.¹⁸⁴⁴ The *Care at the end of life* webpage provides information on:

- understanding care at the end of life
- support for family members and carers
- living with a terminal illness
- what to do after someone dies
- resources for clinicians and health professionals.¹⁸⁴⁵

19.1.3.1 *National Palliative Care Week*

National Palliative Care Week is a major annual event organised by Palliative Care Australia and supported by the Australian Department of Health. The aim of the week is to raise awareness and understanding about palliative care in the Australian community.¹⁸⁴⁶

In its submission to the committee, Palliative Care Queensland recommended the Queensland Government provide statewide grants for palliative care services, peak bodies and community groups to promote palliative care during National Palliative Care Week.¹⁸⁴⁷

19.1.3.2 *Initiatives to increase death literacy*

The committee heard of initiatives being conducted to increase death literacy in the community. Dr John Endacott, Geriatrician and Clinical Services Director of Community Integrated and Subacute Services at the Sunshine Coast Hospital and Health Service, defined 'death literacy' as being a person's 'understanding of what it is to die and what are the options available in terms of having your needs

¹⁸⁴² Private briefing transcript, 6 December 2018, Brisbane, p 11.

¹⁸⁴³ Queensland Government, *Care at the end of life*, <https://www.health.qld.gov.au/news-events/campaigns/previous-campaigns/care-at-the-end-of-life>.

¹⁸⁴⁴ Professor Keith McNeil, Acting Deputy Director-General, Clinical Excellence Division, Queensland Health, Public hearing transcript, 18 October 2019, Brisbane, p 12.

¹⁸⁴⁵ Queensland Government, *Care at the end of life*, <https://www.qld.gov.au/health/support/end-of-life>.

¹⁸⁴⁶ Palliative Care Australia, *National Palliative Care Week 2020*, <https://palliativecare.org.au/national-palliative-care-week-2020>.

¹⁸⁴⁷ Submission 1891, p 6.

met'.¹⁸⁴⁸ Two initiatives to increase death literacy that were raised during the inquiry were Good Life Good Death Expos and Death Cafes.

Good Life Good Death Expos

For over four years, PCQ has conducted free Good Life Good Death Expos.¹⁸⁴⁹ The expos are open to both community and health networks and aim to 'normalise dying, reduce fears and ensure that no-one ever feels a burden to others'.¹⁸⁵⁰ The expos bring together industry experts with the community through education sessions, question and answer panels, exhibition booths and interactive activities.¹⁸⁵¹ In its submission to the inquiry, PCQ explained that '[t]hese events promote community engagement, education and promote service and supports'.¹⁸⁵² In addition, PCQ advised the expos educate health professionals and promote health and social partnerships.¹⁸⁵³

Palliative Care Queensland explained why a person would attend a Good Life Good Death Expo:

Dying is a part of life, which will happen to us all one day – therefore it is best if we can accept and embrace all of life, which includes the end.

...

*This Expo is an opportunity to openly have conversations about end of life – ask questions which are often hard to articulate in a safe and friendly space, open to all ages.*¹⁸⁵⁴

Palliative Care Queensland has conducted Good Life Good Death Expos in Brisbane and Townsville and an expo is planned for Innisfail this year. In its submission to the inquiry, PCQ sought support and funding for the expos.

Death Cafes

A number of stakeholders and submitters referred to the value of Death Cafes in increasing the public's understanding of death and dying. Ms Jane Campbell, Regional Manager of Clinical Strategy and Development at the Central Queensland Wide Bay and Sunshine Coast Primary Health Network, explained to the committee that the primary health network had held death cafes within the community and found them a successful method of raising awareness around death literacy.¹⁸⁵⁵ Ms Samantha King, a Palliative Care Project Officer with the same primary health network, explained further the role of death literacy initiatives and their link to compassionate communities:

*As mentioned, we are trying to increase the public's understanding of death and dying and the literacy around that—so holding things like the death cafe and Death over Dinner within the area, sharing information around death and dying, and trying to make more common those words that make us uncomfortable or are a bit taboo. That kind of flows into compassionate communities. It is not just up to the hospital and health service to provide this service; it is the community. I think the community needs to wrap around each other in this space, especially that unpaid carer workforce. ... We have a huge need to support our unpaid carers at home to do their job.*¹⁸⁵⁶

¹⁸⁴⁸ Public hearing transcript, 3 May 2019, Caloundra, p 11.

¹⁸⁴⁹ PCQ, Good Life Good Death Expo, <https://goodlifegooddeathexpo.org.au/about/>.

¹⁸⁵⁰ PCQ, Good Life Good Death Expo, <https://goodlifegooddeathexpo.org.au/about/>.

¹⁸⁵¹ PCQ, Good Life Good Death Expo, <https://goodlifegooddeathexpo.org.au/>.

¹⁸⁵² Submission 1891, p 34.

¹⁸⁵³ Submission 1891, p 34.

¹⁸⁵⁴ PCQ, Good Life Good Death Expo, <https://goodlifegooddeathexpo.org.au/about/why-attend/>

¹⁸⁵⁵ Public Hearing, 30 October 2019, Gladstone, p 3.

¹⁸⁵⁶ Public Hearing, 30 October 2019, Gladstone, p 6.

Using an example from Warwick, Associate Professor Sarah Winch, the Head of Discipline and Medical Ethics at the University of Queensland, outlined how death cafes can both increase death literacy and increase community involvement in end-of-life care:

*What we are doing with the Death Cafe movement, and we have developed through my charity our own Queensland version which is Wine and Die, is we are really getting people to talk more about end of life, what their options are going to be. At one fantastic Death Cafe I did out at Warwick we actually got groups of people who had been tree changers. They had family but their family were nowhere near them to make decisions so they set up groups where they could say, 'This is my end of life plan. How can we help each other as a community?'*¹⁸⁵⁷

Dying to Know Day

Dying to Know Day is held annually on 8 August. It is organised by The GroundSwell Project, an association committed to building compassionate communities.¹⁸⁵⁸ Aiming to develop death literacy in the community, Dying to Know Day aims to bring about conversations and community actions around death, dying and bereavement.¹⁸⁵⁹

19.2 Community involvement in palliative care

In addition to calls for increased public awareness of palliative care, the committee also heard about the importance of community involvement in palliative care.

Professor Luc Deliens, the Director of the End-of-Life Care Research Group and Professor of Palliative Care Research, Vrije Universiteit Brussel and Ghent University in Belgium explained the importance of a community approach to palliative care:

*We need community approaches to palliative care, because most of our needs will be social needs. Families are shrinking. We used to come from several generations of families where we could take care of each other. In modern society that is not possible anymore, so we need to create new approaches to palliative care that are far more integrated into society. Models like compassionate communities need to be developed and need to be supported. We need compassionate workplaces. We are starting with a compassionate university. We need to reflect on the loss, grief and dying around us.*¹⁸⁶⁰

19.2.1 Queensland Compassionate Communities

Queensland Compassionate Communities is the community arm of PCQ.¹⁸⁶¹ Its mission is to connect and nurture networks around Queenslanders at the end of life.¹⁸⁶² The aim of the compassionate communities program is to 'promote and integrate social approaches to dying, death and bereavement in the everyday life of individuals and communities'.¹⁸⁶³

Palliative Care Queensland advocates for a public health approach to palliative care that includes 'community development to support the dying, those important to them, and those who are

¹⁸⁵⁷ Public Hearing, 5 July 2019, p. 46.

¹⁸⁵⁸ The GroundSwell Project, <https://www.thegroundswellproject.com/>.

¹⁸⁵⁹ Dying to Know Day, <https://www.dyingtoknowday.org/purpose>.

¹⁸⁶⁰ Public hearing transcript, Brisbane, 21 October 2019, p 12.

¹⁸⁶¹ PCQ, Qld Compassionate Communities, See: <https://palliativecareqld.org.au/qcc/>.

¹⁸⁶² PCQ, Qld Compassionate Communities, <https://palliativecareqld.org.au/qcc/>.

¹⁸⁶³ Submission 1891, p 31.

bereaved'.¹⁸⁶⁴ Palliative Care Queensland considers compassionate communities as a core part of a public health approach to palliative care.¹⁸⁶⁵

The Chief Executive Officer of PCQ, Ms Shyla Mills, explained to the committee the compassionate communities model:

I might talk about the Compassionate Communities model. A very new area of palliative care is this model called Public Health Approaches to Palliative Care. Part of that is health promotion models which encourage people to talk about palliative care earlier on. If society was a bit better about talking about it then it has a better effect when you are palliative. It reduces fear by talking about it earlier. That is one of the aspects.

*Another aspect of it which is really important is how you care—how you have a network of care around the person who is dying. Our health model is set up to support the individual, the person, who is dying and what we need to do for them. The Compassionate Communities model is about how do we support the carer and create a network of care around them so they can better care for that person. This is where it involves local government. It involves your constituents. It involves schools to start talking about it. They are little things that are not health models. How does someone mow the lawn for them so they do not have to think about mowing their lawn? Who is going to collect the milk, drop the kids at school or take them to appointments? All of those things could be done by the non-health workforce and by our communities—volunteers and neighbours. There are so many opportunities in that space. Those things do not need to be done by a paid workforce, but part of that is getting society to understand and be open to the fact that we are dying. If you know your neighbour and have those relationships, things could be a lot easier for that carer.*¹⁸⁶⁶

Ms Gillian Hall is the Lead for Compassionate Communities on the Sunshine Coast. Appearing in a private capacity, Ms Hall, a community development practitioner who has been actively working in her community for four years, explained the impact of Compassionate Communities on the Sunshine Coast:

*Since the launch of Compassionate Communities in this region in October 2018 ... We continue to meet regularly and are demonstrating that there is an unmet community need we are addressing that is much bigger than we expected. People want to get together in engaging, interactive, fun ways with people of all ages and abilities and have said they will not come along to formal meetings. They want to be involved in robust discussions and contribute their ideas, stories and experiences about ageing, end of life, death and dying, to debate things like the language used and to share their frustration about the lack of information about death, dying, grieving and living well. Importantly, people want to take action and work on things that matter to them.*¹⁸⁶⁷

The Compassionate Communities Conversations Series is an initiative administered by PCQ in partnership with Carers Queensland, Council on the Ageing Queensland and Health Consumers Queensland.¹⁸⁶⁸ It is funded by a Queensland Government Age-Friendly Queensland grant.¹⁸⁶⁹ The project facilitated open community conversations throughout Queensland about life, ageing and death. In 2019, the Compassionate Communities Conversation Series project travelled throughout Queensland to each Hospital and Health Service region, excluding the Children's Health Network.

¹⁸⁶⁴ Submission 1891, p 31.

¹⁸⁶⁵ Submission 1891, p 31.

¹⁸⁶⁶ Private briefing transcript, Brisbane, 23 January 2019, p. 23.

¹⁸⁶⁷ Public hearing transcript, Caloundra, 3 May 2019, p 17.

¹⁸⁶⁸ PCQ, submission 1891, p. 34.

¹⁸⁶⁹ PCQ, submission 1891, p. 34.

Community members, community groups, organisations and health professionals participated in the discussions.¹⁸⁷⁰ The events ‘provided information and resources about local services and supports available to people who are experiencing loss, ageing, dying or grief and improved death and compassion literacy’.¹⁸⁷¹ Evaluation of the Compassionate Communities Conversation Series found:

- 81 percent of respondents had increased awareness of what community supports and services were available to them in relation to loss, ageing, dying and grief
- 81 percent of respondents had increased confidence to start conversations about loss, ageing, dying and grief
- 78 percent of respondents had increased acceptance that loss, ageing, dying and grief were a part of life and that the reality of dying and death can help them to prepare for the end of life in ways that are meaningful to them.¹⁸⁷²

In its submission to the inquiry, PCQ requested support to implement the recommendations identified during the Compassionate Communities Conversation Series at both the Hospital and Health Service and State level.¹⁸⁷³

19.2.2 Ambulance Wish Queensland

A recent initiative led by PCQ is the Ambulance Wish Queensland program, which seeks to ‘give people living with a terminal illness the resources, specialist transport and medical care they need to fulfil their final wishes’.¹⁸⁷⁴ Palliative Care Queensland states:

Wishes can be simple, a last visit home or to a place of personal significance. It’s usually the little things that mean the most to a person nearing the end of their life.

*We are excited to welcome this unique and heart warming charity to Queensland Australia. With medically trained volunteers and adapted ambulances we fulfil the desires of those who are in need of assistance to experience one final wish.*¹⁸⁷⁵

The Queensland Government is supporting this program by:

*...providing a decommissioned ambulance vehicle and seed funding of \$55,000 to support Palliative Care Queensland ... The government’s contribution assists Palliative Care Queensland to complete its recruitment and training of volunteers, enabling wishes to be fulfilled, hopefully, from late 2019—later this year.*¹⁸⁷⁶

¹⁸⁷⁰ PCQ, *Compassionate Community Conversation Series Report 2019*, p 14.

https://palliativecareqld.org.au/wp-content/uploads/2019/12/Compassionate-Community-Conversation-Series-Report-2019_Book.pdf.

¹⁸⁷¹ PCQ, *Compassionate Communities Conversation Series: Queensland 2019*, p 35,

https://palliativecareqld.org.au/wp-content/uploads/2019/12/Compassionate-Community-Conversation-Series-Report-2019_Book.pdf.

¹⁸⁷² PCQ, *Compassionate Communities Conversation Series: Queensland 2019*, p 18,

https://palliativecareqld.org.au/wp-content/uploads/2019/12/Compassionate-Community-Conversation-Series-Report-2019_Book.pdf.

¹⁸⁷³ Submission 1891, p. 34.

¹⁸⁷⁴ PCQ, *Ambulance Wish Queensland*, <https://ambulancewishqld.org.au/>.

¹⁸⁷⁵ PCQ, *Ambulance Wish Queensland*, <https://ambulancewishqld.org.au/>.

¹⁸⁷⁶ Professor Keith McNeil, Acting Deputy Director-General, Clinical Excellence Division, Queensland Health, public hearing transcript, Brisbane, 18 October 2019, p 12.

19.3 Future directions

In addition to general calls for increased awareness, during the inquiry the committee heard recommendations of specific initiatives to improve community awareness, to increase death literacy and to increase community involvement in palliative care.

In its submission, PCQ included recommendations to activate the community to be more involved in palliative care.¹⁸⁷⁷ Palliative Care Queensland stated that implementation of that strategy should include grants for community groups to enable community-based palliative care initiatives,¹⁸⁷⁸ and to support and educate the community. These are summarised in the table below.

Table 24: Palliative Care Queensland Recommended community initiatives

Initiative	Benefits
Implement the La Trobe University Health End of Life Program (HELP) in Queensland	This community development program would create a collaborative community culture that attends to local end-of-life care needs. Communities are guided through practical suite of resources on how to work with carers, families, friends and neighbours to support residents who wish to receive end-of-life care in home or community setting
Create a statewide palliative care volunteer training and support hub	Effective training is critical to the recruitment, activity and retention of volunteers in palliative care. A statewide training hub would promote consistency and connectedness for volunteers. Training would build confidence and competence. Ongoing support and networking for volunteers would connect them into a more integrated effort.
Create a compassionate schools program	Compassionate Schools are primary and senior schools that embed compassionate communities models in their school systems. It would create an opportunity for schools to provide a network of support around people experiencing loss, aging, dying and grief within their school community.
Implement the Last Aid courses throughout Queensland	Last Aid courses are a simple and effective concept to teach the public about palliative care to enhance public discussion about death and dying. The current course includes modules on Care at the End of Life, Advance Care Planning and Decision making, Symptom Management and Cultural Aspects of Death and Bereavement.
Develop an online self-care and compassion training course for community members and health professions	The development of a free online course that allows individuals, community groups and health professionals to understand compassion and self-care, particularly in relation to end of life, would promote community wellbeing.

Source: Submission 1891, *Palliative Care Queensland*, pp 32–33.

Committee Comment

The committee considers public awareness and community involvement in palliative care vital in reducing fear and misconceptions about end-of-life and palliative care as well as providing better outcomes for patients and their loved ones. Education is needed across the community about palliative care and dying to enable the community to support those who wish to die at home.

The committee acknowledges the exceptional work being done by Palliative Care Queensland and others to promote and normalise discussions about death and dying. It appreciates the initiatives already in place to increase death literacy and the importance of the compassionate communities' response in supporting the dying.

The committee commends the recent initiative by Palliative Care Queensland and the Queensland Ambulance Service, supported by the Queensland Government, to facilitate the Ambulance Wish Queensland program.

However, it is clear to the committee that more needs to be done to create public awareness of palliative care and enable a community-based palliative care approach.

¹⁸⁷⁷ Submission 1891, p 6.

¹⁸⁷⁸ Submission 1891, p 6.

Recommendation 66 Palliative care community education strategy

The committee recommends that the Queensland Government work with relevant stakeholders to develop a community awareness campaign to promote palliative care and increase knowledge of services available to patients and carers.

Recommendation 67 Community understanding of death, dying and options for end-of-life care

The committee recommends that the Queensland Government support Palliative Care Queensland and other stakeholders to increase the community's understanding of death, dying and options for end-of-life care.

Recommendation 68 Support for community initiatives

The committee recommends that the Queensland Government consider supporting the community initiatives recommended by Palliative Care Queensland in their submission.¹⁸⁷⁹

¹⁸⁷⁹ See submission 1891.

20 Planning for when capacity is lost

Queenslanders have the opportunity to plan ahead for their future through a range of Advance Care Planning (ACP) documents that enable them to appoint an attorney to make decisions on their behalf and give directions about their future health care if they subsequently lose capacity.¹⁸⁸⁰ This chapter discusses the ACP process, its benefits, and barriers and challenges to implementation as identified by inquiry stakeholders.

20.1 What is Advance Care Planning?

Queensland Health describes Advance Care Planning (ACP) as a ‘person-centred approach for planning current and future health and personal care that reflects the person’s values, beliefs and preferences’.¹⁸⁸¹ ACP is an entirely voluntary process.¹⁸⁸²

The Queensland Health *Advance Care Planning Clinical Guidelines* (ACP Clinical Guidelines) establish best practice for ACP in Queensland. The guidelines state:

*Effective ACP involves ongoing communication between the person, those closest to them, and a multidisciplinary healthcare team to optimise the person’s current treatment, care, and quality of life. If the person becomes too unwell to participate in decision-making, the preparation gained through ACP will guide all those involved in the process to make decisions about health and personal care in the person’s best interests.*¹⁸⁸³

Ms Debbie D’Urso, an ACP facilitator, explained that ACP is based on the fundamental principles of dignity, alleviation of suffering, self-determination and autonomy.¹⁸⁸⁴

Queensland Health stated that ‘Advance care planning is usually undertaken within a health or aged care setting and with the assistance of trained professionals after an individual has been diagnosed with a life-limiting condition’.¹⁸⁸⁵ The ACP Clinical Guidelines acknowledge that while ACP can take place at any time, discussions should ideally take place as early as possible to optimise a person’s quality of life.¹⁸⁸⁶

Advanced Care Planning is a broad, iterative process which can comprise a number of stages and may include:

- *assessing the person’s current condition and likely prognosis*
- *establishing the person’s health and personal goals, values and preferences*
- *discussing current and future treatment and personal care options*
- *identifying the person’s decision-makers for a time when they might lack capacity for decision-making*
- *documenting treatment and care plans and ensuring they are appropriately communicated and available when needed*

¹⁸⁸⁰ Private briefing transcript, Mrs Leanne Robertson, Assistant Director-General, Strategic Policy and Legal Services, Department of Justice and Attorney-General, Brisbane, 23 January 2019, p 33.

¹⁸⁸¹ Queensland Health, *Advance Care Planning Clinical Guidelines*, January 2018, p 5.

¹⁸⁸² Public briefing transcript, Dr John Wakefield, then Deputy-Director General, Clinical Excellence Queensland, Department of Health, Brisbane, 5 April 2019, p 1.

¹⁸⁸³ Queensland Health, *Advance Care Planning Clinical Guidelines*, January 2018, p 5.

¹⁸⁸⁴ Public hearing transcript, Townsville, 29 May 2019, p 4.

¹⁸⁸⁵ Queensland Health, correspondence dated 23 January 2019, *Briefing on aged care, palliative care and legal documents relevant to end-of life care in Queensland*, p 26.

¹⁸⁸⁶ Queensland Health, *Advance Care Planning Clinical Guidelines*, January 2018, p 5.

- *assisting the person to formally document their wishes if they choose to do so*
- *coordinating treatment and care to reflect the person's goals, values and preferences*
- *medical officers documenting clinical recommendations regarding resuscitation*
- *providing copies of formal documentation to substitute decision-maker(s), carers, family, GP and any other healthcare providers as appropriate*
- *reviewing decisions.*¹⁸⁸⁷

20.2 Benefits of Advance Care Planning

A number of inquiry stakeholders highlighted the benefits of Advance Care Planning.¹⁸⁸⁸

The ACP Clinical Guidelines note that research has confirmed the following benefits and outcomes of ACP in the context of planning for optimal current and future health care. ACP:

- *reduces unnecessary aggressive treatments at the end of life, and results more often in care that is consistent with the person's goals*
- *affects patient care in positive ways, for example being able to achieve a "good death"*
- *achieves a higher satisfaction with quality of care*
- *reduces hospitalisations for patients at the end of life, particularly for nursing home residents by between 40 per cent to 80 per cent and can lead to a threefold increase in palliative care referrals*
- *increases the likelihood that clinicians and families understand and comply with a person's wishes*
- *diminishes the likelihood of stress, anxiety, and depression in surviving relatives*
- *improves the incidence [of] family meetings with decision-makers when a person is at the end of life*
- *invokes earlier initiation of more appropriate palliative care, which improves symptoms and mood, reduces undesired use of invasive interventions and life-sustaining treatments, lowers the likelihood of in-hospital death, prolongs life of higher quality and reduces use of resources that do not benefit patients*
- *reduces moral distress among healthcare providers.*¹⁸⁸⁹

For Professor Elizabeth Reymond, Palliative Care (Advance Planning Office Lead), Department of Health, one of the most important benefits of ACP was that people had talked about their wishes with their families and loved ones:

*The great value of them [advance care planning processes] is that it usually means that people have spoken to their important others. People have spoken to their families, the people they love, about what they want so nobody has to make these decisions in a crisis, which is the worst time to make healthcare decisions, really. That is the true value, I believe, of the advance care planning processes.*¹⁸⁹⁰

¹⁸⁸⁷ Queensland Government, Queensland Health, *Advance Care Planning*, <https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/patient-safety/end-of-life/advance-care-planning>

¹⁸⁸⁸ See, for example, submissions 1203, 1208, 1891.

¹⁸⁸⁹ Queensland Health, *Advance Care Planning – Clinical Guidelines*, 2018, p 9.

¹⁸⁹⁰ Public briefing transcript, Brisbane, 5 April 2019, p 4.

Palliative Care Queensland also highlighted the importance of ACP stating, it ‘is an essential component of quality palliative care and needs to be incorporated into all models of care to ensure client-centred care and high-value outcomes for Queensland’.¹⁸⁹¹

Explaining that the end of life can be a difficult, confusing and painful time for an individual, their carers and health professionals, PCQ advised that a lack of understanding and documentation of the personal choices can result in unwanted outcomes. Furthermore, ‘[t]he absence of a clear end-of-life decision and treatment pathway for the client can also lead to futile care and inappropriate use of health care resources’.¹⁸⁹²

Dr Bill Lukin, a Community Palliative Care Consultant at Metro North HHS, provided the following illustrative example to demonstrate how the absence of forward planning, even with an Advance Care Plan, could result in unwanted outcomes:

*If at two o'clock in the morning your mum wakes up and she is really breathless or she has pain and you say, 'Is it okay not to send her to hospital? If so, we want to give her morphine,' it has to be written up and it has to be available. The nurses cannot just suddenly decide that you are not going to hospital and they are going to give you morphine. That has to be thought about beforehand. One of the areas where we probably fall down is that the general practitioner might do the advance care plan but not do the things that flow on from that—which is: what happens at two o'clock in the morning when mum wakes up and she is in pain? An ambulance gets called, they are taken to hospital.*¹⁸⁹³

20.3 Advance Care Planning documentation

Advance Care Planning includes the process of documenting the outcomes of ACP discussions and a person’s goals of care. Many topics can be covered during ACP discussions, including:

- *the person’s wishes, preferences or fears in relation to their current or future treatment and care*
- *the feelings, beliefs or values that may be influencing a person’s preferences and decisions*
- *family members, those close to the person or other substitute decision-makers that the person would like to be involved in decisions about their care*
- *resuscitation planning, involving conversation about interventions that may be considered or undertaken in an emergency, such as CPR*
- *formally documenting preferences for a time when decisional capacity becomes impaired*
- *the benefits of ACP, such as when it may be helpful to make decisions in advance or appoint someone trusted to make decisions on the person’s behalf*
- *wishes in relation to funerals, the handling of their body (including cultural needs), and their beliefs or values about organ or tissue donation.*¹⁸⁹⁴

A person can choose to document their wishes in a number of ways. Some documents are legally binding, whilst others are not. In any case, the process of documentation is optional and voluntary for the person involved.¹⁸⁹⁵

¹⁸⁹¹ Submission 1891, p 36.

¹⁸⁹² PCQ, Submission 1891, p 36.

¹⁸⁹³ Private briefing transcript, Brisbane, 6 December 2018, p 4.

¹⁸⁹⁴ Queensland Health, Advance Care Planning – Clinical Guidelines, 2018, p 17.

¹⁸⁹⁵ Queensland Health, Advance Care Planning – Clinical Guidelines, 2018, p 19.

Queensland Health advised that across Australia, including Queensland, the uptake of ACP is low.¹⁸⁹⁶ However, Dr John Wakefield, Queensland Health, advised that Queensland is 'leading the way' in the curation of end-of-life documents (discussed further below).¹⁸⁹⁷ Dr Wakefield estimated that 2,200 patients per month in Queensland have ACP documents completed.¹⁸⁹⁸

Key ACP documents are discussed below.

20.3.1 Advance health directives

An Advance Health Directive (AHD) is a formal document in which an adult provides direction about current and future health matters.

An AHD is a legally binding document made in accordance with the *Powers of Attorney Act 1998* (Qld). In terms of legal hierarchy, the AHD takes priority over other ACP documents¹⁸⁹⁹ and, generally, must be followed if it has been documented corrected.¹⁹⁰⁰

An AHD outlines what medical treatment or health care a person wants if they can no longer make decisions.¹⁹⁰¹ This can include a decision about the withholding or withdrawal of life-sustaining measures.¹⁹⁰²

An AHD can only be acted on when a person loses capacity.¹⁹⁰³ At least three people must be involved in the preparation of an AHD including the individual, a doctor, and an appropriate witness (such as justice of the peace, commissioner for declaration, a lawyer, or a notary public).¹⁹⁰⁴

An AHD form can outline a person's general instructions, or identify specific medical treatments that the person does not wish to receive, under certain circumstances.¹⁹⁰⁵ Mrs Leanne Robertson, Assistant Director General, Department of Justice and Attorney General (DJAG) advised that given the gravity of these decisions, Queensland guardianship legislation imposes additional statutory criteria:

*Firstly a direction to withhold or withdraw a life-sustaining measure will not operate unless the adult has no reasonable prospect of regaining capacity for the matter. The adult must also be either terminally ill or have a condition that is incurable or irreversible and is reasonably likely to die within a year or be in a persistent vegetative state or permanently unconscious. Further, where a direction relates to withholding or withdrawing artificial nutrition or artificial hydration, the direction will only operate if the commencement or continuation of the measure would be inconsistent with good medical practice.*¹⁹⁰⁶

Representatives of DJAG advised that the department is currently reviewing AHD and Enduring Power of Attorney forms (discussed below), as part of implementation work associated with the *Guardianship and Administration and Other Legislation Amendment Act 2019*. This work is to

¹⁸⁹⁶ Professor Elizabeth Reymond, Palliative Care (Advance Planning Office Lead), Department of Health, Public briefing transcript, Brisbane, 5 April 2019, p 5.

¹⁸⁹⁷ Private briefing transcript, Brisbane, 6 December 2018, p 11.

¹⁸⁹⁸ Private briefing transcript, Brisbane, 6 December 2018, p 11.

¹⁸⁹⁹ *Guardianship and Administration Act 2000*, s 66.

¹⁹⁰⁰ For the formal requirements of an Advance Health Directive, see *Powers of Attorney Act 1998*, s 44. For exceptions to the rule that an AHD must be followed, see *Powers of Attorney Act 1998*, s 36.

¹⁹⁰¹ Private briefing transcript, 23 January 2019, pp 33-34.

¹⁹⁰² Mrs Leanne Robertson, Assistant Director General, Strategic Policy and Legal Services, Department of Justice and Attorney General, Private briefing transcript, 23 January 2019, pp 33-34.

¹⁹⁰³ Public briefing transcript, Brisbane, 5 April 2019, p 4.

¹⁹⁰⁴ Queensland Government, Department of Justice and Attorney-General, Advance Health Directive form, p 4.

¹⁹⁰⁵ Queensland Government, Advance Health Directive, <https://www.qld.gov.au/law/legal-mediation-and-justice-of-the-peace/power-of-attorney-and-making-decisions-for-others/advance-health-directive>.

¹⁹⁰⁶ Private briefing transcript, Brisbane, 23 January 2019, p 34.

include the development of explanatory guides for the forms, and capacity guidelines to assist people assess a person's capacity.¹⁹⁰⁷ Discussion of the additional statutory criteria limiting the operation of AHDs and their impact on medical decision making is covered in Chapter 21.

20.3.2 Enduring Power of Attorney

An enduring power of attorney document (EPoA) is a legally binding document that is used to appoint someone to make financial and personal decisions on behalf of a person if they become unable to make their own decision.¹⁹⁰⁸

The EPoA has two different forms: a short form, which is used if a person wishes to appoint the same attorney for both financial and personal (including health care) matters; and a long form which can be used by a person if they wish to appoint different attorneys for financial and personal matters.¹⁹⁰⁹ As is the case for AHDs, these documents must also be signed in front of a qualified witness.¹⁹¹⁰

20.3.3 Statement of choices

A popular alternative to AHDs is a statement of choices (SoC) made under common law. The statement of choices document 'allows individuals to record their personal values and wishes for future healthcare'.¹⁹¹¹ The document was introduced as a result of the low uptake of AHDs by patients.¹⁹¹²

Queensland Health advised:

*The statement of choices document is not legally binding or a substitute for an advance health directive. As a values-based document, it provides guidance to substitute decision-makers about a person's wishes and choices for care if the person is unable to communicate their choices at a time when required.*¹⁹¹³

Professor Reymond, Department of Health, advised that 'people find them very useful', and provided the following example to illustrate the benefit of their use:

*I was at a residential aged-care facility with a woman who had clearly lost capacity. She was very demented and in a lot of distress. Her husband was the enduring power of attorney. The two children—one in New Zealand, one in Brisbane—were at loggerheads and so there was discussion with the enduring power of attorney, who was the legal decision-maker. He wanted to do one thing but wanted to make sure it was okay with the kids. We had the person in New Zealand telephoning in and there was that crisis point, and there was a lot of tension between the children. By actually reading the statements that had been written in the statement of choices, it just allowed the children to back off from their personal agendas and to get focused on the person who needed the care. They are valuable documents.*¹⁹¹⁴

However, inquiry participants expressed a number of issues with the use of the Advance Care Planning documentation, and these are discussed at section 20.5.4 below.

¹⁹⁰⁷ Private briefing transcript, Brisbane, 23 January 2019, p 35.

¹⁹⁰⁸ Private briefing transcript, 23 January 2019, p 34.

¹⁹⁰⁹ Queensland Government, Power of Attorney, <https://www.qld.gov.au/law/legal-mediation-and-justice-of-the-peace/power-of-attorney-and-making-decisions-for-others/power-of-attorney>

¹⁹¹⁰ The Public Advocate, submission 1208, pp 17-18.

¹⁹¹¹ Queensland Health, correspondence dated 23 January 2019, *Briefing on aged care, palliative care and legal documents relevant to end-of life care in Queensland*, p 30.

¹⁹¹² Queensland Health, correspondence dated 23 January 2019, *Briefing on aged care, palliative care and legal documents relevant to end-of life care in Queensland*, p 30.

¹⁹¹³ Queensland Health, correspondence dated 23 January 2019, *Briefing on aged care, palliative care and legal documents relevant to end-of life care in Queensland*, p 30.

¹⁹¹⁴ Public briefing transcript, Brisbane, 5 April 2019, p 5.

The committee heard of instances where conflicts arise as a result of differing instructions within different ACP documents. The committee questioned Professor Reymond about such circumstances:

Where they do not align, yes, and that is true and that does happen. The advance health directive is only relevant to four different situations. The statement of choices is much broader, so you can get conflict there. The way we would resolve that is really by looking at the words in the statement of choices and trying to get an idea of who that person was and what they would want and then relate it back to the AHD but knowing all the time that that is the legal document. All of these conversations help to resolve those sorts of conflicts.

*The other way you can get conflict is that these documents are not time limited. Although with the AHD and also the statement of choices we suggest regularly updating them, they can get stuck in time. You may find an AHD that was written 10 years ago and people may have a statement of choices that was done six months ago. Now, it would be easy to argue that the statement of choices is the much more relevant, contemporaneous document; nonetheless, the AHD is still the legally enshrined document.*¹⁹¹⁵

20.4 Initiatives to enhance advance care planning in Queensland

The committee was advised of a number of initiatives implemented by Queensland Health to enhance ACP in Queensland. Information on these initiatives is provided below.

20.4.1 Office of Advance Care Planning

The Office of Advance Care Planning (Office of ACP) was established by Queensland Health to promote the importance of ACP processes. The service provides assistance with ACP information and resources for patients, carers, family members and health professionals.¹⁹¹⁶

The Office of ACP is also responsible for adding Advance Care Planning documents to the Queensland Health electronic hospital record (known as The Viewer). The Office of ACP receives copies of the various ACP documents from individuals, HHSs, GPs, and residential aged care facilities across Queensland and reviews them. If the documents are complete, they are uploaded to The Viewer.¹⁹¹⁷ The Viewer has a portal for ACP documents called the ACP Tracker app. Using the ACP Tracker, GPs and hospital clinicians can access all ACP documentation in one location.¹⁹¹⁸ Queensland is the first state or territory in Australia to have a statewide, standardised clinical approach to receive, review and upload Advance Care Planning documents.¹⁹¹⁹ Dr Wakefield explained that evidence shows that 'Queensland has more of those documents curated on [The Viewer] available to clinicians and GPs than the rest of the country combined'.¹⁹²⁰

Professor Reymond advised that there are currently over 20,000 ACP documents in the Viewer.¹⁹²¹ The majority of these are SoCs as shown in the Figure below.

¹⁹¹⁵ Professor Elizabeth Reymond, Deputy Clinical Director, Palliative Care (Advance Planning Office Lead), Department of Health, public briefing transcript, Brisbane, 5 April 2019, p 5.

¹⁹¹⁶ Queensland Health, correspondence dated 23 January 2019, *Briefing on aged care, palliative care and legal documents relevant to end-of life care in Queensland*, p 26.

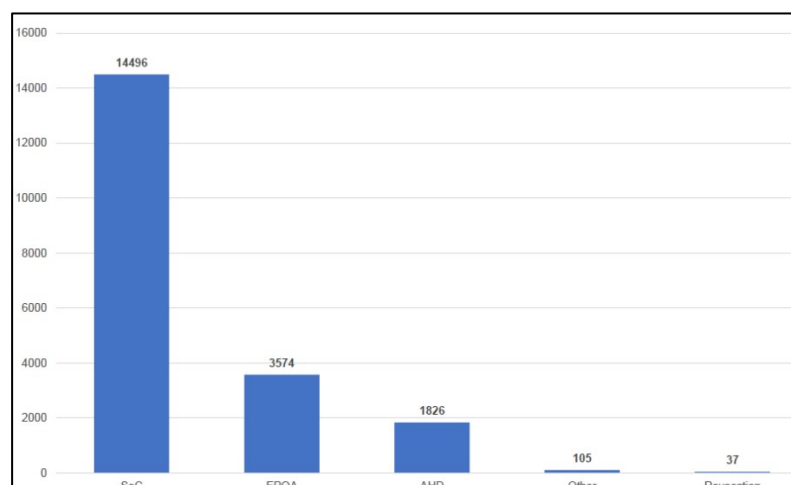
¹⁹¹⁷ Queensland Government, My Care, My Choices, Advance Care Planning, About Us, <https://metrosouth.health.qld.gov.au/acp/about-us>.

¹⁹¹⁸ Professor Elizabeth Reymond, Deputy Clinical Director, Palliative Care (Advance Planning Office Lead), Department of Health, public briefing transcript, Brisbane, 5 April 2019, p 3.

¹⁹¹⁹ Queensland Government, My Care, My Choices, Advance Care Planning, About Us, <https://metrosouth.health.qld.gov.au/acp/about-us>.

¹⁹²⁰ Private briefing transcript, 6 December 2018, Brisbane, p 11.

¹⁹²¹ Public briefing transcript, Brisbane, 5 April 2019, p3.

Figure 5: Types of documents loaded to The Viewer

Source: Tabled paper, Queensland Health, A system for ACP in Queensland, presentation, public hearing on 5 April 2019.

Reflecting on the possible reasons for the relatively small number of AHDs stored on The Viewer compared to SoCs, Professor Reymond explained:

*The advance health directives have not really taken off. It is hard to know where they are being stored but, in terms of availability to clinicians when they are needed, not that many people have advance health directives if you measure it that way. I think in part it is because the document is so long and it has fairly high-level language in it.*¹⁹²²

In addition to initiatives to enhance the capture of documentation, Dr Wakefield also advised of a number of initiatives undertaken to inform and upskill the community and practitioners, including the Care at the end-of-life website and public advertising campaigns. Dr Wakefield added:

*That was accompanied by a range of other targeted pieces of work around general practitioners. A thousand general practitioners and surgeries were provided with information as well as all the residential aged-care facilities, providing the sort of information that we are talking about here.*¹⁹²³

20.4.2 Advance Care Planning facilitators

Advance Care Planning facilitators (ACP facilitators) are people who are experienced in having sensitive ACP discussions. Professor Reymond explained that the purpose of these positions 'is not to get a document' but rather to 'raise awareness of the benefits of ACP'¹⁹²⁴. ACP facilitators were introduced in a number of HHSs in Queensland as part of the Queensland Health Quality Improvement Program for ACP.¹⁹²⁵

Palliative Care Queensland outlined its support for the ongoing use of ACP facilitators, stating:

The value of dedicated ACP facilitators has been demonstrated recently across Queensland with a project funded through a time-limited Quality Improvement Payment. Findings were significant.

Compared with people who did not complete an ACP, those who did complete an ACP, with the assistance of an ACP facilitator, in accordance with their wishes:

¹⁹²² Public briefing transcript, Brisbane, 5 April 2019, p 5.

¹⁹²³ Private briefing transcript, Brisbane, 6 December 2018, p 11.

¹⁹²⁴ Public briefing transcript, Brisbane, 5 April 2019, p 3.

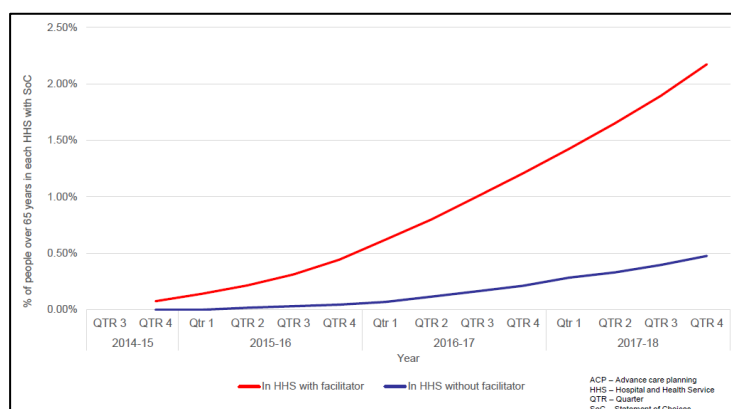
¹⁹²⁵ Public briefing transcript, Brisbane, 5 April 2019, p 3

- were significantly more likely to die out of hospital
- spent significantly fewer days in hospital in their last 6 months of life; and
- were less likely to be admitted to ICU in their terminal admission.

Findings also showed that the earlier in a person's illness trajectory that an advance care plan was completed, the less time they spent in a hospital.¹⁹²⁶

Queensland Health confirmed these findings, and also advised of the uplift in the uptake of SoCs in HHSs with dedicated ACP facilitators, compared to those HHSs without dedicated staff.¹⁹²⁷ The figure below illustrates this comparison.

Figure 6: Impact on SoC completion: HHSs with dedicated ACP facilitators compared with HHSs without dedicated staff



Source: Tabled paper, Queensland Health, A system for ACP in Queensland, presentation, public hearing, 5 April 2019.

The committee also heard from Ms Debbie D'Urso, an Advanced Care Planning facilitator at Townsville Hospital. Ms D'Urso talked of her experiences as a facilitator and advised that the appointment of the facilitator position had assisted to raise the profile of Advance Care Planning; however, she also advised that there is still a lot more work to be done:

*The appointment of an advance care planning facilitator has assisted to raise the profile of advance care planning across the health service and community. There is a lot more work to be done to compassionately inform the community about advance care planning and especially reduce their fears of discussing death and dying. The progress of changing community attitudes will take time and a commitment from all involved.*¹⁹²⁸

20.5 Challenges and barriers to advance care planning

While the committee heard much positive evidence relating to ACP in Queensland, inquiry stakeholders reported a number of challenges associated with its implementation. Key issues are discussed below.

20.5.1 Death is not discussed

As is the case for palliative care, one of the primary barriers to ACP identified by inquiry participants was that people do not talk about death. In its submission to the inquiry, the AMA Queensland stated:

¹⁹²⁶ Submission 1891, p 36.

¹⁹²⁷ Queensland Health, A system for ACP in Queensland, presentation, public hearing on 5 April 2019.

¹⁹²⁸ Public hearing transcript, Townsville, 29 May 2019, p 5.

*The predominant barrier to effective advance care planning is the societal and cultural stigma attached to discussions around death and dying. Despite the inevitability of death, many of us avoid thinking about our own mortality, or serious illness, until it is too late.*¹⁹²⁹

To address the ‘cultural and societal stigma’ surrounding death and dying, AMA Queensland called for investment ‘in a public education campaign to improve consumer literacy and knowledge about the issue’. The goal of the campaign would be to normalise discussions about Advance Care Planning among a variety of cultural and societal groups.¹⁹³⁰

The Grattan Institute in its submission to the committee, contended that the ‘public is ill informed and overly optimistic about the effectiveness of health care’ as a result of limited public discussion.¹⁹³¹ The organisation also called for a comprehensive national education campaign that would ‘focus on encouraging people to discuss their preferences and choices for end-of-life care with health professionals, including GPs’.¹⁹³²

The issue was also acknowledged by Professor Reymond, Department of Health, who advised that a ‘major cultural shift’ was required to address the issue:

*[W]e can talk about lots of things and sometimes we talk about wills, but we do not talk about us actually ending our lives—between a death-denying public and clinicians who actually perceive death as some sort of treatment failure. ...That is a major cultural shift that needs to occur across both the public and the clinicians. I would like to say that it took 23 years to stop X-raying pregnant women. This sort of cultural shift that we are asking for is much larger and it will take a longer time.*¹⁹³³

20.5.2 Complexity and adequacy of documentation process

Some inquiry stakeholders suggested that the ACP documentation process and the legal framework within which it operated was overly complicated for both individuals and health workers.

The Public Advocate contended the availability of various ACP documents (AHD, EPoA, and SoC) had the ‘effect of creating some confusion and uncertainty about what documents take priority and how they can be identified and recorded in appropriate systems for access when necessary’.¹⁹³⁴ In particular, ‘the Statement of Choices form and the Acute Resuscitation Plan complicate the Advance Care Planning process, particularly as they do not have formal legal status’.¹⁹³⁵

The Public Advocate advised that the availability of multiple documents has led to a number of detrimental situations. This included cases where people:

- *have multiple advance care planning documents which potentially conflict with each other, which may result in their wishes not being taken into account, or being applied differently from what was intended when they originally prepared the documents*
- *complete a Statement of Choices form under the misapprehension that it will override or revoke an earlier Enduring Power of Attorney, when it does not*
- *complete a Statement of Choices form with a representative of a Health and Hospital Service that is recorded on the Queensland Health electronic filing system, while having a valid*

¹⁹²⁹ Submission 1233, AMA Queensland’s Health Vision, Part Five, p 4.

¹⁹³⁰ Submission 1233, AMA Queensland’s Health Vision, Part Five, p 7.

¹⁹³¹ Submission 24, p 25.

¹⁹³² Submission 24, p 25.

¹⁹³³ Public briefing transcript, Brisbane, 5 April 2019, p 2.

¹⁹³⁴ Submission 1208, p 19.

¹⁹³⁵ The Public Advocate, submission 1208, p 18.

*Enduring Power of Attorney document, and the hospitals and medical practitioners acting on the Statement of Choices document rather than consulting the person's Attorney.*¹⁹³⁶

Dr Will Cairns, a retired specialist palliative care clinician and former Statewide Clinical Lead for Care at the End of Life, expressed similar concerns. Dr Cairns advised that ACP documents (SoC, AHD and EPoA) were 'cumbersome, inadequate and/or flawed'. Dr Cairns explained:

*At various times over the past few years a wide range of clinicians and lawyers have expressed to me their concerns about the design and function of all current ACP documents (SoC, AHD and EPoA). They are cumbersome, inadequate and/or flawed. There is no unifying agreed narrative that shapes the experience of ACP for the patient in a coherent and legally effective manner. They are not understood by a large proportion of healthworkers, let alone the general public.*¹⁹³⁷

The committee received correspondence from Professor Alan Berry, the Chair of the Health, Quality and Safety Commission in New Zealand who advised on the ACP system used in New Zealand.¹⁹³⁸

He stated:

The advance care plan captures a person's treatment and care preferences, goals values and beliefs. It may also include advance directives. An advance directive gives a consent or refusal to specific treatment for a future time when the person is unable to communicate consent or refusal themselves.

*If the plan includes a valid advance directive, that refusal or consent to a procedure or treatment (for example, 'not for resuscitation') would be legally binding if valid.*¹⁹³⁹

The ACP guide used in New Zealand has the advantage of providing for items covered in the Queensland SoC and AHD, and is therefore less complex. Professor Berry, also referred to comments received from ACP users in that country:

*Many users find the plan works extremely well for them; other feedback is that it is quite long and there is too much contextual information. A project is currently underway to separate the contextual information (inside part of each page) from the information template (the form on the outer side of each page); and also to develop contextual information that is more appropriate for Māori and other groups.*¹⁹⁴⁰

However, in New Zealand advance directives made at common law are legally binding. See Section 20.5.3 for a discussion on the operation of common law health directives in Queensland.

Dr Cairns, also reflected on different ACP practices across the various health care providers, noting that as patients cross boundaries from one part of the healthcare system to another:

*... carefully considered and prepared documents that describe decisions may not be respected. This is a serious risk for patients who may not receive the care that they have decided upon and for doctors and other staff who are unable to know that they are doing the right thing by their patient.*¹⁹⁴¹

¹⁹³⁶ Submission 1208, p 19.

¹⁹³⁷ Submission 1940, p 9.

¹⁹³⁸ Correspondence, from Professor Alan Berry, Health, Quality and Safety Commission New Zealand, dated 20 May, 2019.

¹⁹³⁹ Correspondence, from Professor Alan Berry, Health, Quality and Safety Commission New Zealand, dated 20 May, 2019, p 1.

¹⁹⁴⁰ Correspondence, from Professor Alan Berry, Health, Quality and Safety Commission New Zealand, dated 20 May, 2019, p 3.

¹⁹⁴¹ Submission 1940, p 10.

AMA Queensland advised of the complexities caused as a result of the different laws and terminologies that exist across Australian jurisdictions, noting that ‘laws that guide advance care plans and advance health directives within Queensland and across the country are inconsistent and confusing’.¹⁹⁴² AMA Queensland continued that:

- *The current state of the law may cause confusion for health workers, patients and families, particularly when there is interstate movement*
- *The current jurisdictional differences make a national database impractical.*¹⁹⁴³

The legal complexities around the delivery of end-of-life and palliative care are discussed further in section 21.5.1.

20.5.3 Status of advance directives made at common law

A common law advance directive is:

*A common law Advance Directive is an Advance Directive created and governed by the common law (i.e. decisions made by judges in the courts). Under a common law Advance Directive a person can specify their wishes about future health care and medical treatment, including treatment at the end of life. These Directives differ from statutory Advance Directives, which are created by legislation.*¹⁹⁴⁴

A statement of choices is an example of an advance directive made at common law. According to Wilmott and White common law advance directives are not legally binding in every Australian State or Territory:

- *In New South Wales and Tasmania, common law Advance Directives are the only Advance Directives that exist and are legally binding.*
- *In the Australian Capital Territory, the Northern Territory, South Australia and Western Australia both statutory Advance Directives and common law Advance Directives are legally binding.*
- *In Victoria common law Advance Directives that refuse treatment and statutory Advance Directives are binding.*
- *In Queensland, only statutory Advance Directives are legally binding.*¹⁹⁴⁵

While the *Powers of Attorney Act 1998* does not prevent directives being made at common law, there is ambiguity as to whether the *Guardianship and Administration Act 2000* prevents consent to, or refusal of, health care which is not in an AHD.¹⁹⁴⁶ This could negate an Advance Care Planning document such as a patient’s Statement of Choices.¹⁹⁴⁷

¹⁹⁴² AMA Queensland, submission 1233, p 3 of attachment, *AMA Queensland’s Health Vision. Part five: care at the end of life*.

¹⁹⁴³ AMA Queensland, submission 1233, p 3 of attachment, *AMA Queensland’s Health Vision. Part five: care at the end of life*.

¹⁹⁴⁴ Queensland University of Technology, End of Life Law in Australia, Common Law Advance Directives, <https://end-of-life.qut.edu.au/advance-directives/common-law-advance-directives>.

¹⁹⁴⁵ Queensland University of Technology, End of Life Law in Australia, Common Law Advance Directives, <https://end-of-life.qut.edu.au/advance-directives/common-law-advance-directives>.

¹⁹⁴⁶ Queensland Law Reform Commission 2010, A review of Queensland’s Guardianship Laws, 2010, Executive Summary, p xii, <https://www.qlrc.qld.gov.au/publications>.

¹⁹⁴⁷ Queensland Health advised that the ‘SOC is not a legally binding document or a substitute for an AHD’. Rather, ‘it provides guidance to substitute decision makers about a person’s wishes for care if the person is unable to communicate their choices at a time when required’.

In 2010, the Queensland Law Reform Commission (QLRC) raised concerns about the operation of the *Guardianship and Administration Act 2000*:

*The continued operation of the common law in this area is especially important in supporting the role that advance care planning plays in the care of adults who have a terminal illness by ensuring that decisions made at a time when they are competent will continue to be effective even if they reach the stage that they no longer have the capacity to make to decisions about their health care.*¹⁹⁴⁸

The QLRC recommended reform in this area so that ‘guardianship legislation does not affect what would otherwise be recognised at common law as an effective consent to, or refusal of, health care’.¹⁹⁴⁹ In its correspondence to the committee, the Department of Justice and the Attorney-General advised that it is not currently reviewing this recommendation and noted that reviewing and implementing this recommendation is a matter for the government to consider.¹⁹⁵⁰

20.5.4 Accessibility of ACP documentation

Some inquiry stakeholders representing treating clinicians reported concerns about the accessibility of the range of ACP documents when needed. This was particularly true in times of emergency.

AMA Queensland stated:

*Even where a principal has made a legally valid advance care plan there are difficulties over providing the treating clinicians with a copy. While a will can be kept at a safety deposit box, to be retrieved by the executor of the estate as necessary, it is counterproductive to store an advance care plan in the same manner. Treating clinicians either have no advance care plan, where one exists, or an old or outdated care plan. These inconsistencies erode confidence in their usage as clinicians instead revert to standard clinical guidance, even if it is contrary to the wishes espoused in the inaccessible advance care plan.*¹⁹⁵¹

Dr Elizabeth Whiting, Executive Director, Clinical Services, Metro North Hospital and Health Service, agreed, and highlighted the following situation:

*Part of the problem is if the individual does not declare or does not remember that they have an AHD and you are in a time of crisis. Part of the challenge is that we cannot find them. Where are they? When I was doing my will, my lawyer was going to put it in his filing system in his office. That is of no use when I end up in the emergency department with a cardiac arrest.*¹⁹⁵²

Palliative Care Queensland contended that there is a ‘clear need for systematised approach to information sharing and to create quick, easy visibility to ACP documents to frontline clinicians with added reassurance about document validity’, and welcomed recent initiatives by Queensland Health to improve the accessibility of documents.¹⁹⁵³

20.5.5 Funding available for ACP activities

Some inquiry stakeholders advised the uptake of ACP was limited by the existing funding arrangements for ACP activities.

¹⁹⁴⁸ Queensland Law Reform Commission 2010, A review of Queensland's Guardianship Laws, 2010, Executive Summary, p x, <https://www qlrc.qld.gov.au/publications>.

¹⁹⁴⁹ Queensland Law Reform Commission 2010, A review of Queensland's Guardianship Laws, 2010, Summary of recommendations, p xxi, <https://www qlrc.qld.gov.au/publications>.

¹⁹⁵⁰ Correspondence from DJAG dated 19 February 2020, attachment p. 6.

¹⁹⁵¹ AMA Queensland, submission 1233, p 4.

¹⁹⁵² Public briefing transcript, Brisbane, 5 April 2019, p 10.

¹⁹⁵³ Submission 1891, p 36.

Professor Elizabeth Reymond, Deputy Clinical Director, Palliative Care (Advance Planning Office Lead), advised that there is no dedicated Medicare Benefits Schedule (MBS) GP item number for Advance Care Planning.¹⁹⁵⁴ AMA Queensland also raised the issue and called for the establishment of MBS rebates to properly remunerate clinicians for taking the time to complete ACP with their patients:

*The Queensland Government should commit to discussing, with the Federal Government, the establishment of dedicated MBS rebates to properly remunerate clinicians for taking the time to step through advance care planning with their patients. While AMA Queensland does not believe that clinicians are currently neglecting this planning for financial reasons it is important that they are appropriately compensated for having difficult conversations that can reduce the burden on the health system.*¹⁹⁵⁵

Professor Elizabeth Reymond, also advised there is no activity based funding attributed to Advance Care Planning in Queensland HHSs and that this ‘can make HSSs hesitant in taking on the job’.¹⁹⁵⁶

20.5.6 Support for health professionals to have ACP discussions

Some inquiry participants contended that further work was required to ensure that health professionals were adequately supported to have ACP discussions and were clear as to their respective responsibilities.

AMA Queensland reported that there can be uncertainty about who within a multi-disciplinary health care team should initiate ACP discussions:

*Where there are complex co-morbidities there may be several members of the treatment team that are each waiting on the other to initiate the conversation. The general practitioner, who in many cases has known the principal for the longest period, could be waiting for the specialist to raise the issue. The specialist, who is managing the condition that requires advance care plans, may feel that it is inappropriate to raise it given their comparatively limited engagement with the patient. Both clinicians may be waiting for the principal, and their family, to raise the issue. The end result is that the treating team doesn’t have the vital discussion of advancing care planning before it’s too late because they all believe it’s more appropriate if someone else raises it.*¹⁹⁵⁷

The Grattan Institute noted that one of the barriers to ACP was that health professionals are uneasy about discussing death and dying with patients, noting that ‘[a]s a result they can obfuscate about likely treatment outcomes and overestimate the chances of recovery. Often they do not feel they have the required skills to have these hard conversations’.¹⁹⁵⁸

This issue was acknowledged by Queensland Health. Professor Reymond stated:

*...in general, everybody else says that it is somebody else’s job, so really it becomes nobody’s business. The residential aged-care facilities say that these plans should have been done when they were in the community. The GPs say, ‘We don’t know their prognosis; this is a hospital job.’ The hospitals say, ‘We simply don’t have time because we have 10-minute outpatient appointments. This has to go with the general practitioner.’ It just goes around.*¹⁹⁵⁹

¹⁹⁵⁴ Public briefing transcript, 5 April 2019, p 2.

¹⁹⁵⁵ Submission 1233, p 6.

¹⁹⁵⁶ Public briefing transcript, 5 April 2019, p 2.

¹⁹⁵⁷ Submission 1233, p 4.

¹⁹⁵⁸ Submission 24, pp 14-15.

¹⁹⁵⁹ Public briefing transcript, Brisbane, 5 April 2019, p 4.

Committee comment

The committee recognises the value and importance of Advance Care Planning for ensuring that people's wishes are known and respected at the end of life. Making plans and discussing those plans with loved ones is particularly important when a patient is entering palliative care. It assists family members and reduces the risk of unwanted outcomes at what can already be a difficult time.

The committee welcomes efforts by Queensland Health to enhance Advance Care Planning in Queensland. In particular, evidence received during the inquiry demonstrated the value added by Advance Care Planning facilitators.

However, the committee also heard that there are a number of barriers to people participating in Advance Care Planning, including a reluctance to discuss death, the complicated Advance Care Planning documentation process, the status of advance directives made at common law, the accessibility of Advance Care Planning documents for medical practitioners, the funding available for Advance Care Planning documentation and support for health professionals to have Advance Care Planning discussions.

The committee acknowledges the work undertaken to date to promote and normalise discussions around death; however, it is clear more needs to be done. The committee recommends that the Queensland Government continue to work with relevant stakeholders to roll out a public education campaign to promote awareness of Advance Care Planning.

The committee notes evidence received by inquiry stakeholders that the existing Advance Care Planning documentation process is considered complex and confusing. The committee acknowledges the work being undertaken by Department of Justice and Attorney-General to review Advance Health Directives and Enduring Power of Attorney Forms, and believes it is imperative the Queensland Government ensures documentation is simple and accessible for users and health professionals.

To reduce the ambiguity regarding advance care directives made at common law, the committee is of the view that the *Guardianship and Administration Act 2000* should be amended to reflect the premise that decisions made and recorded by a person as part of a formally documented Advance Health Directive or a common law directive at a time when they have competency should be respected in full by doctors and other health service providers after the person has lost capacity.

The committee welcomes recent initiatives undertaken by Queensland Health to enhance the accessibility of patient Advance Care Planning documents for health professionals. However, it would appear that treating clinicians are still experiencing difficulties accessing relevant documents in a timely manner, particularly in emergency situations. This situation needs to be rectified to avoid uncertainty and unwanted medical care being provided.

It is also important that health professionals are supported and understand their responsibilities as they relate to Advance Care Planning.

Despite the recognition of the importance of Advance Care Planning and the efforts made to encourage people to undertake this process, the committee notes the absence of dedicated MBS rebates to properly remunerate clinicians for assisting patients with Advance Care Planning. This should be addressed to remove an obvious impediment to clinicians in all settings working with patients to ensure they have an Advance Care Planning in place.

Recommendation 69 Implement public education campaigns

The committee recommends that the Queensland Government work with relevant stakeholders to roll out a public education campaign to promote awareness of Advance Care Planning and its benefits amongst the community and within the health service to encourage people to discuss their preferences and choices for end-of-life care with health professionals.

Recommendation 70 Simplify Advance Care Planning documents

The committee recommends that Queensland Health continue to work with the Department of Justice and Attorney-General to ensure that Advance Care Planning documents are simple and accessible for users and health professionals.

Recommendation 71 Amend the *Guardianship and Administration Act 2000*

The committee recommends that the Queensland Government consider amending the *Guardianship and Administration Act 2000* to ensure that directives made at common law are legally binding.

Recommendation 72 Improve clinician access to Advance Care Plans

The committee recommends that the Queensland Government continue to roll out its system for registering advance care documents on The Viewer to ensure they can be accessed when necessary by treating clinicians, especially in times of emergency.

Recommendation 73 Promote clinician use of The Viewer

The committee recommends that the Queensland Government continue to promote the use of The Viewer to health professionals, so that its benefits can be more fully realised.

Recommendation 74 Dedicated Medicare Benefits Schedule rebates for advance care planning

The committee recommends that the Australian Government introduce dedicated Medicare Benefits Schedule rebates for clinicians undertaking Advance Care Planning activities with their patients.

Recommendation 75 Simplify advance care planning guidelines for health professionals

The committee recommends that the Queensland Government amend and simplify existing Advance Care Planning guidelines for health professionals to ensure that they understand their responsibilities as they relate to Advance Care Planning and can effectively undertake these responsibilities.

21 How effective is end-of-life and palliative care?

This chapter examines the effectiveness of end-of-life and palliative care by providing information on the benefits of palliative care and management of symptom control. Where symptoms are not adequately managed, a patient may refuse treatment or nutrition and hydration. End-of-life and palliative care presents challenges for health professionals in understanding the law relating to the practice of palliative sedation and medical decision making when capacity is lost. Lack of understanding of these complex legal areas may lead to the under-treatment of some patients and the consequential lack of adequate symptom relief.

21.1 A 'good death': the benefits of end-of-life and palliative care

While a 'good death' means something different for each person, studies indicate that a good death involves control of preferences for the dying process, a pain free status, and emotional well-being.¹⁹⁶⁰ Palliative care seeks to address these concerns. According to the Cancer Council, the benefits of palliative care for cancer patients are:

- the reduction of cancer symptoms, which may include pain, fatigue, nausea and constipation,
- the slowing of the growth or spread of cancer,
- the provision of access to counselling and support services to address fears, worries or conflicting emotion, and
- the provision of counselling and support to ascertain a patient's goals such as end-of-life wishes, or making the most out of each day.¹⁹⁶¹

Chief Executive Officer of Palliative Care Queensland who is a paediatric palliative care nurse, Ms Shyla Mills explained palliative care as follows:

*When people no longer feel that they have to fight a disease, beat a condition or attend medical appointments and tests in the hope of getting better, when they most often know that they will not, they are given a chance to have important conversations, shift their focus to what matters most and prepare for the end before they become too weak and frail. Palliative care does not rob people of time; it allows them to refocus their goals and conserve their energy so that they do have time for the things that matter most, instead of using that precious time to attend medical appointments and tests, and spending their superannuation on treatments that are highly unlikely to be effective.*¹⁹⁶²

Board Member of Karuna Hospice Services, Dr Michael Bolton AM, outlined the work of palliative care teams in a similar way:

*... what palliative care teams do is try to use as little medication as is necessary to achieve their purpose, which is, as I said before, comfort, quality of life and so on. Accomplishing that is our, if you like, raison d'être. The reason we are there is comfort and quality of life, and we use what we need to use to ensure peace and comfort at the end of life, the terminal phase. Sometimes that is a lot of drugs; most often it is not. I do not think anyone actually does overdose for the sake of it.*¹⁹⁶³

¹⁹⁶⁰ Emily A. Meier, Ph.D., Jarred V. Gallegos, M.A., Lori P. Montross-Thomas, Ph.D., Colin A. Depp, Ph.D., Scott A. Irwin, M.D., Ph.D., and Dilip V. Jeste, M.D., *Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue*, *Am J Geriatr Psychiatry*. 2016 April, 24(4), p 5.

¹⁹⁶¹ The Cancer Council, *When can palliative care help?* <https://www.cancer.org.au/about-cancer/treatment/palliative-care.html>.

¹⁹⁶² Private briefing transcript, Brisbane, 23 January 2019, p 17.

¹⁹⁶³ Public hearing transcript, Brisbane, 18 October 2019, p 7.

At the Hervey Bay hearing, palliative care nurse, Ms Judy Allen, spoke of her experiences in working in palliative care and the benefit of a palliative care approach:

*The palliative care nurse or the person delivering care can sit and listen. Not a lot of people have a lot of time in their working life to just sit and listen. I remember when I first started doing community palliative care work. My friends at the hospital would often say to me, 'What do you say to these people who are dying?' I had to sit and think. I do not know. Often I say nothing; I just sit and listen. A lot of the time, all that people who are dying need is for someone to listen to their problems. If you can alleviate some of their problems and they are peaceful, that is the definition of palliative care.*¹⁹⁶⁴

Former nurse, Ms Kathleen McMonagle, made a submission espousing the benefits of good palliative care.

*I am a retired registered nurse who worked for many years in Aged Care and in a sub-acute hospital. I have been with many people (and their families) at the end of life. With good palliative care they are able to die with dignity and peace, with the families able to experience closure and connection with the dying and each other.*¹⁹⁶⁵

In its submission to the committee, Palliative Care Australia noted the economic benefits of providing people with palliative and end-of-life care:

*...people who receive palliative care compared with those receiving usual care, have less hospitalisations, shorter lengths of hospital stay, reduced use of Intensive Care Units (ICUs) and fewer visits to Emergency Departments (EDs). Cost-savings from palliative care interventions occur across a number of settings including delivery at home, in hospital, in residential aged care, for cancer and non-cancer life-limiting illnesses and early versus late delivery of care.*¹⁹⁶⁶

Several inquiry witnesses and submitters to the inquiry also commented on the benefits of palliative care. Ms Wendy Francis, the Queensland Director of the Australian Christian Lobby told the committee about the excellent palliative received by her sisters:

I will tell you about my two sisters. My sister Dianne was diagnosed with pancreatic cancer when she was 50 years old. She died 10 months later at home with family, having received amazing palliative care. I walked that journey with her and will be forever grateful to the palliative care nurses and doctors.

...

My sister Karen was diagnosed with an inoperable brain tumour when she was 59. We had her with us for 14 months after that diagnosis. Again, the palliative care she received is enough to still make me cry with gratitude today.

*As I said, she died in St Vincent's hospital. My sisters received amazing palliative care whilst surrounded by their family and friends.*¹⁹⁶⁷

Inquiry submitter, Ms Helen Chan, commented on the benefits of palliative care for her mother:

¹⁹⁶⁴ Public hearing transcript, Hervey Bay, 15 July 2019, p 11.

¹⁹⁶⁵ Submission E1162, p 1.

¹⁹⁶⁶ Palliative Care Australia, *The Economic Value of Palliative Care and End-of-Life Care*, Economic Research Note 1, July 2017, p 1, https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2017/07/PCA019_Economic-Research-Sheet_1a_General.pdf.

¹⁹⁶⁷ Public hearing transcript, Brisbane, 23 August 2019, p 26.

*My mother also benefited from good palliative care in Royal Brisbane Hospital in the last 2 weeks of her life. The medical team ensured that she was in as little pain as possible and the nurses were caring and compassionate.*¹⁹⁶⁸

21.2 Are symptoms adequately managed?

Pain is just one of the symptoms that a person may suffer at the end of their life. Other symptoms include fatigue, loss of appetite, breathing difficulties, bowel problems and insomnia and nausea.¹⁹⁶⁹ The following sections discuss the views of stakeholders and health professionals on the adequacy of symptom control at the end of life.

21.2.1 Stakeholder views on symptom management

Many inquiry stakeholders noted that at the end of life, there are some circumstances where end-of-life care cannot help with symptom management. At the public hearing in Hervey Bay, Mr Paul Smith told the committee about the incredible pain endured by his son Corey, despite the best efforts of the medical team.

*I lost my son Corey at 28 to cancer in March this year in the Hervey Bay Hospital. Corey was suffering from cancer for about 18 months. It was a rare, aggressive form. ... He had such a high pain threshold. Those last few hours will be with me for the rest of my life and are the most horrible I have ever seen. I feel for the medical staff who were there. There were four people trying to find a way to arrest his pain. I have read that the Queensland palliative care doctors say that nobody is suffering in palliative care. That is absolute nonsense and I will not take it. Even post-mortem his muscles were still activating in pain. When a nurse turns around and tells you we have given him enough medication to put down a horse and yet you are holding your son who is skin and bones and he is in tremendous amounts of pain that is unacceptable. It is undignified and that is not the way we treat any living being in this world.*¹⁹⁷⁰

Ms Annabelle Vaughan, told the committee about the pain her father suffered at the end of his life.

*My darling dad, who even with the best palliative care available in the state, was still distressed, nauseous and uncomfortable almost to the end. He was given terminal sedation due to his pain and distress, yet it still took 10 days from when he lost consciousness to when he died. We sat by his side providing what little comfort we could for 10 days. If you have not walked that road, then you have absolutely no concept of how torturous it is. The inadequacy, anger and deep shame that I felt then still burns just as much today as it did when I watched helplessly from my family members' bedsides.*¹⁹⁷¹

Similarly, Mr Warren Smith, in his submission to the committee, commented on the pain of a friend dying from breast cancer. He explained that neither morphine nor good palliative care could alleviate her suffering.¹⁹⁷²

Dr Evelyn Jansen told the committee about the suffering her husband John endured over the last three weeks of his life:

He had a tumour on the spine that had begun to compress the spinal cord. The prognosis was agonising pain, advancing paralysis and then death. He had gone through all the treatment he

¹⁹⁶⁸ Submission E1701, p 1.

¹⁹⁶⁹ PCOC, University of Wollongong, *Palliative care at a glance in Queensland*, web report, 2018 p 5. <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow259482.pdf>.

¹⁹⁷⁰ Public hearing transcript, Hervey Bay, 15 July 2019, p 16.

¹⁹⁷¹ Public hearing transcript, Southport, 10 Sep 2019, p 29.

¹⁹⁷² Submission 200, p 1.

could manage...the statement of choices...was circulated to health authorities. John had written—

‘I would not want to be forced to linger as a prisoner in a hospice or hospital bed needlessly suffering until the inevitable end. I have seen family members in this situation and would not want this for me. What would give me comfort when nearing death? Knowing in advance that the end of my life will be pain-free, peaceful and quick.’

...

*when his pain could no longer be managed at home. He was relatively comfortable for the first couple of weeks, but on 14 June he lost control of his legs, bladder and bowel and from then on he was a needlessly suffering prisoner. He was dead from the chest down, mortified at what he was putting his kind and caring nurses through in their efforts to clean him up, in constant and increasing pain and wishing to die. He suffered in this state for three full weeks until 5 July, sedated but distressed and agitated until the end.*¹⁹⁷³

A number of stakeholders described symptoms other than pain that were experienced by their loved ones at end-of-life. In her submission, Ms Suzanne Thwaites gave an account of the death of her father who had suffered from a stroke:

*...his Dr ...informed me my dad was beyond a road to any type of recovery due to the brain damage from the stroke. On my insistence they transferred my father by ambulance to the hospital nearly three hours away. The staff treated my father the best they could following their required protocol, I sat by my father’s side for the next thirteen days and night, he could not speak, drink or swallow, he lay paralysed, his tears begging me to help him, I cried with him during the horror of staff having to put a suction tube down his throat every four hours to remove built up fluid he was unable to swallow. I kept telling him it was against the law for me to do anything that would take his life, he cried with me so I knew he could understand what I was saying.*¹⁹⁷⁴

In her submission, former registered nurse of 48 years and president of Dying With Dignity, Ms Jos Hall, shared details of the symptoms suffered by her father:

*A week before he died, he started vomiting faecal fluid. His abdomen had swollen to the size of a heavily pregnant woman, and his arms and legs looked like photos that you see of people in Japanese prisoner of war camps. The vomiting was extraordinary – he vomited litres at a time. We used a bucket and it seemed like he would half fill it. It was projectile vomiting, and the faecal fluid would splash on his clothes and bedding. The smell was unbelievable. I’ve been a nurse for 48 years and I have smelt a lot of faeces, but this was a sick smell. This wasn’t just the smell of faeces – it was the smell of something rotting.*¹⁹⁷⁵

A submitter whose name was withheld also wrote to the committee describing the multitude of symptoms suffered by her father that were not adequately managed.

His limbs became swollen with fluid, and he cried from severe cramps. At first we tried to massage his legs, but it got to a stage where even trimming his nails would bring him to tears. He went from oral pain killers to morphine intravenously, then put onto Fentanyl patches in addition to the morphine driver. Even with all of these in place, Dad’s pain levels were out of control.

When he soiled himself the nurses would have to wait for a ‘top-up’ to kick in before they could roll him over to clean his backside. He constantly begged us to call for a doctor, and on many

¹⁹⁷³ Public hearing transcript, Brisbane, 13 September 2019, p 71.

¹⁹⁷⁴ Submission 244, p 1.

¹⁹⁷⁵ Submission 1882, p 1.

*occasions they refused his request for a top-up, saying he was at his maximum levels. We argued with one doctor in particular who said it was 'unethical' to give a patient too much morphine as it would affect his breathing, however we believed it is unethical to leave a patient writhe in pain. Dad's pain levels were uncontrollable, and his quality of life non-existent. He wanted to die, but the doctors were unable to grant his wish, forcing him to take control of the situation by refusing to take his Parkinson's medication (suggested to him by... as a way of 'speeding up' the process). He had already stopped taking his staph antibiotics (in the hope the staph would flare up and end his life quickly) as well as his blood thinners (hoping for another stroke, this time fatal), but ironically neither of these occurred. By refusing the Parkinson's medication meant his swallow reflex would be affected, and if he was unable to swallow then his body would slowly shut down from the lack of nutrition and hydration, or he could effectively 'drown' as he was unable to swallow his spit. Although Dad's local GP was extremely vocal in his objection of this decision, Dad was adamant he didn't want to lie there any longer. He was clear headed and fully informed when he refused the medication on the next round. My sister and I were at Dad's side when he finally passed away, 7 weeks and 3 days after his stroke. His death was not peaceful and was horrifying to watch. He did indeed drown in his own phlegm as his GP had warned.*¹⁹⁷⁶

21.2.2 The views of health professionals on symptom management

Health practitioners were divided on the ability of end-of-life and palliative care to manage pain levels at the end-of-life. There was also disagreement about the number of patients whose symptoms could not be adequately managed. Dr Bill Lukin, a consultant working for the Community Palliative Care Service of the Metro North Hospital and Health Service advised the committee:

... one of the reasons I love palliative care is that I can help every single patient I see. ...

*In regard to the patient you were talking about who is lying in a bed screaming and we cannot stop them screaming, that does not really happen. ... I can think of two off the top of my head in the Royal Brisbane over the last five years, and we would have seen thousands and thousands and thousands of patients. It is a very small proportion of the patients that we see.*¹⁹⁷⁷

Asked whether it would be true statement to say that given access to good quality palliative care—no one needs to die in excruciating pain, Dr Lukin replied:

*Yes, that would be correct. Could you say, 'Absolutely nobody—not one person ever again in the history of the world'? Clearly not. Interestingly, that pain comes about not necessarily from physical causes but existential. In specialist palliative care as a multidisciplinary group with the patient and their family, a lot of that suffering is not in the bed; it is around the bed in the family. Our job is to deal with the whole family as a unit. That is one of the other big differences with palliative care. It is not just the patient; it is the people around them who are our patients as well, because how they cope afterwards will really depend on how this goes.*¹⁹⁷⁸

Dr Louise Welch, the Clinical Director of Palliative Care at the Sunshine Coast Hospital and Health Service, told the committee:

We always say to our patients that we never promise that we will completely relieve suffering in all cases—that would be quite unwise—but we tell our patients that we will try our hardest. Yes, there are always very few—not many, but very few—who will persist in their request to have their life ended. That will always be the case, I believe. ... we must protect those people who may

¹⁹⁷⁶ Submission E622, p 1.

¹⁹⁷⁷ Private briefing transcript, 6 February 2018, p 6.

¹⁹⁷⁸ Private briefing transcript, 6 February 2018, p 6.

*be wavering between one or the other because of an unmet need, but there will always be those people for whom, for whatever needs, their suffering is not met by anybody or anything.*¹⁹⁷⁹

In contrast, Dr Edward Mantle from the Cairns and Hinterland Hospital and Health Service stated: ‘I think it is disingenuous, and it is probably closer to a bald-faced lie, when palliative physicians say that they can relieve all suffering for all patients. It is simply not true.’¹⁹⁸⁰

In her submission to the committee, palliative care nurse practitioner Ms Faye Tomlin advised,

*... I have watched many Queenslanders take their last breath. This is what I know for certain, Medicine continues to promote life prolonging measures at all cost without quality of life consideration. Palliative care can never fully take away the pain or reduce the symptom burden that is caused by many advanced disease states.*¹⁹⁸¹

According to Palliative Care Outcome Collaboration (PCOC),¹⁹⁸² ‘each year in Australia, about 160,000 people die and around 100,000 of these deaths are predictable. Of those, 40,000 patients receive specialist palliative care and 60,000 do not’.¹⁹⁸³ In terms of the numbers of people who receive palliative care and whose symptoms are not adequately managed, the PCOC data showed:

*Over 80% of patients receiving palliative care do not have severe symptoms at the time of death. Only a small proportion experience severe symptoms and evidence shows these symptoms either become absent or mild as death approaches. When patients are referred to palliative care about 9% experience severe pain but this reduces to approximately 2% prior to death. Patients in their final days and hours receiving palliative care experience less pain, symptoms and problems than earlier in their illness.*¹⁹⁸⁴

Although two per cent of people experiencing severe pain just prior to death may appear minor, based on the information above, it translates to 500 people per year. That figure does not take into consideration the numbers of people experiencing severe distress from symptoms other than pain.¹⁹⁸⁵

The table below represents data collected by PCOC in 2018. It measured severe symptoms at the beginning of an episode-of-care and just before death, for patients who received palliative care in Queensland. The data demonstrated that 10.3% of patients reported feeling severe distress due to fatigue at the start of their palliative care. This was followed by pain (9.0%) and breathing issues (6.2%) The table indicates that across these symptoms, the incidence of severe distress reduced just before death. However, the data also shows that there are some patients whose symptoms are not adequately managed despite receiving palliative care.

¹⁹⁷⁹ Public hearing transcript, Caloundra, 3 May 2019, p 15.

¹⁹⁸⁰ Public hearing transcript, Cairns, 27 May 2019, p 8.

¹⁹⁸¹ Submission 287, p 2.

¹⁹⁸² The Australian Palliative Care Outcomes Collaboration (PCOC) is a national palliative care outcomes and benchmarking program. PCOC’s primary objective is to systematically improve patient outcomes (including pain and symptom control).

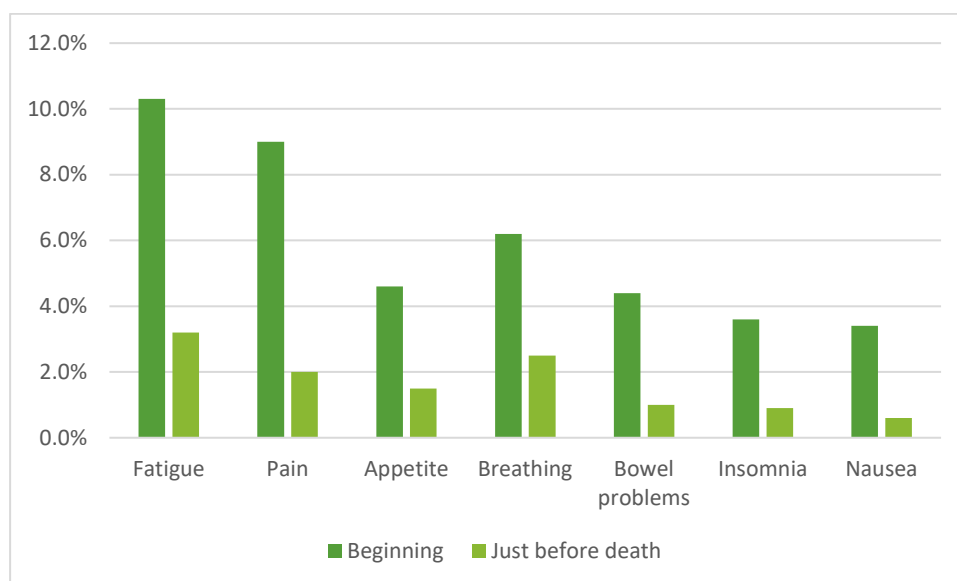
<https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow251762.pdf>.

¹⁹⁸³ PCOC, University of Wollongong, *Key messages for PCOC services, clinicians and researchers*, <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow241304.pdf>.

¹⁹⁸⁴ PCOC, University of Wollongong, *Key messages for PCOC services, clinicians and researchers*, <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow241304.pdf>.

¹⁹⁸⁵ See Table 23 Severe symptoms at beginning of episode-of-care and just before death, for patients who received palliative care in Queensland, 2018.

Figure 7: Severe symptoms at beginning of episode-of-care and just before death, for patients who received palliative care in Queensland, 2018



Source: PCOC, University of Wollongong, *Palliative care at a glance in Queensland*, web report, 2018 p 5, accessed 25 February 2020 from <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow259482.pdf>.

In its key messages for PCOC services, clinicians and researchers, PCOC also reported:

*The evidence shows palliative care is highly effective. Fatigue is the most common symptom that causes patients distress.... Distress from fatigue and appetite is not surprising as a loss of energy and appetite is common as death approaches.*¹⁹⁸⁶

While the chart above provides a breakdown of symptom types at end-of-life, Mr Phil Brown, a palliative care nurse who estimated that he had provided end-of-life care to around 2,000 people in their final days, gave a more descriptive account of some of the distressing symptoms other than pain that he had witnessed:

...Sometimes it's been impossible to relieve these shocking symptoms:

- 1. Excessive respiratory secretions - Where the person is gurgling with every breath and their noisy struggle for breaths can be heard some distance down the corridor. Every breath is a major battle and it's absolutely exhausting. There is medication to treat this, but I have seen medication fail to work adequately, leaving patients in a state of panic as (patients have told me) they feel like they are drowning. As death approaches, the "death rattles" can be very pronounced.*
- 2. Faecal vomiting caused by a bowel obstruction - I will never forget seeing patients vomiting their own faeces ... repeatedly. The look of horror on their face, and the smell, is forever etched in my memory. This is a devastating symptom that can be impossible to control without surgery (and these patients are way too sick to even consider surgery). What do you say to a previously large-framed man who is now an emaciated bag of bones weighing 45 kg, with vomited faeces dripping from his chin, who desperately grabs your arm in an exhausted state while "vomiting" and tells you they just want to die?*
- 3. Large fungating ulcers - I've seen numerous patients with large cavernous ulcerating wounds caused by advanced cancers invading previously healthy tissue. I recall one patient who had a massive invasive tumour of her vulva. The cancer had spread and she was now in palliative care, dying. The skin where her vulva had once been, had broken down, with a wound so deep that*

¹⁹⁸⁶ PCOC, University of Wollongong, *Key messages for PCOC services, clinicians and researchers*, <https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow241304.pdf>

you could insert part of your fist inside the crater. Necrotic (dead) tissue and puss lined the wound causing a constantly weeping foul-smelling discharge. The smell could not be disguised despite packing the wound with odour-absorbing dressings, and absolutely nothing could mask the smell of rotten flesh. In addition to being in disgraceful pain, this poor woman was distressed that her family had to endure the shocking smell when they visited her.

...

I must give special mention to neuro-degenerative conditions. These are a class of medical conditions that prevent normal functioning of the nervous system, and includes conditions such as Multiple Sclerosis, Motor Neurone Disease, Parkinsons disease, Huntingtons disease etc. I've nursed many people with these particularly cruel conditions that rob their victims of their basic dignity for a prolonged period - often years - during their terminal decline, leading to their inevitable death. These people can have symptoms including:

- *Progressive or total loss of muscle control - including the ability to move their limbs, scratch themselves or to speak normally.*
- *Progressive or total loss of ability to swallow food and fluids, including their own saliva.*

*These people, who can be young, are trapped in a body that doesn't work for even the most basic daily functions and for a long time prior to their inevitable death, are totally reliant on other people. I have had people with these medical conditions tell me that they do not want to live like this and they wish to die.*¹⁹⁸⁷

A general surgeon from Toowoomba, Dr Timothy Porter, made a submission along similar lines.

*Patients suffering recurrence of their cancer may have obstruction of their bowel leading to massive abdominal distension and vomiting. If they have had surgery in their last weeks, they will occasionally suffer the development of fistulae from their abdominal wounds where they have bowel content discharging through and onto their skin. This can often be very difficult to control. Control of associated odour can be very difficult, leading to such patients having the added burden of embarrassment at their personal situation. Patients may experience local recurrence of their cancer such as in their breast or chest wall where their breast was. Again this may lead to a situation where there is massive leakage of fluid which is difficult to control and again where odour is a major issue for them.*¹⁹⁸⁸

21.3 When symptoms cannot be controlled: the use of palliative sedation

As indicated by the PCOC data many people receive adequate symptom control at the end of life. However there are some circumstances where symptom control can be achieved only through palliative sedation.

21.3.1 What is palliative sedation?

According to Morita Tatsuya et al (2002), palliative sedation (sometimes referred to as terminal sedation) is commonly described as 'the use of sedative medications to relieve intolerable and refractory distress by the reduction in patient consciousness.'¹⁹⁸⁹ The Queensland University of Technology's *End of life Law in Australia* website notes that palliative sedation:

...is used in palliative care for several reasons, including to manage refractory symptoms (symptoms which cannot be otherwise adequately controlled) at the end of life. The primary

¹⁹⁸⁷ Submission 977, pp 6-7.

¹⁹⁸⁸ Submission E1795, p 1.

¹⁹⁸⁹ Morita, Tatsuya et al, Definition of Sedation for Symptom Relief, *Journal of Pain and Symptom Management*, 2002, Volume 24, Issue 4, p 447.

*purpose of palliative sedation is to sedate a patient near the end of their life in order to relieve their symptoms, not to cause or hasten their death.*¹⁹⁹⁰

Others have described palliative sedation as involving an explicit decision to render the patient unconscious to prevent or respond to otherwise unrelievable physical distress.¹⁹⁹¹ This can be described as intensive symptom management.¹⁹⁹² Life-sustaining treatment is withheld because it could prolong the dying process without contributing to the patient's quality of life.¹⁹⁹³

21.3.2 Does palliative sedation hasten death? Are there legal protections?

There is some debate around whether palliative sedation hastens the death of a patient, likening it to a form of euthanasia. The ethical rationale for the use of palliative sedation is derived from the principle of double effect, otherwise known as the doctrine of double effect.

In Queensland the doctrine of double effect is legislated in section 282A of the *Criminal Code Act 1899*. Section 282A provides that a person is not criminally responsible for providing palliative care to another person even if the incidental effect is to hasten a person's death. The section states:

- (1) *A person is not criminally responsible for providing palliative care to another person if—*
 - (a) *the person provides the palliative care in good faith and with reasonable care and skill;*
 - (b) *the provision of the palliative care is reasonable, having regard to the other person's state at the time and all the circumstances of the case; and*
 - (c) *the person is a doctor or, if the person is not a doctor, the palliative care is ordered by a doctor who confirms the order in writing.*
- (2) *Subsection (1) applies even if an incidental effect of providing the palliative care is to hasten the other person's death.*¹⁹⁹⁴

Section 282A(2) provides that, if the primary intention is to relieve pain and symptoms, not cause death, the person who gave the medication will not be criminally responsible for a death which follows, even if it is foreseen.¹⁹⁹⁵

There is no specific requirement that the person be near death for the section 282A defence to apply. However, their condition, including whether they are close to death, would be relevant when the health professional considers whether providing the palliative care is 'reasonable'.¹⁹⁹⁶

McGhee (2004) suggests that:

Under the legislation, the prosecution could succeed in negating a defence to murder or manslaughter if it could show that the care was not reasonable, that is, in accordance with what is accepted as good medical practice in Australia, or if the care was provided by someone other than a doctor without the written authority of a doctor. These additional requirements were

¹⁹⁹⁰ Queensland University of Technology, End of Life Law in Australia, Palliative Medication, <https://end-of-life.qut.edu.au/palliative-care>.

¹⁹⁹¹ Quill, Timothy E and Byock, Ira R. (2000) 'Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids', *Annals of Internal Medicine*, vol 132, no. 5, p 409.

¹⁹⁹² Quill, Timothy E and Byock, Ira R. (2000) 'Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids', *Annals of Internal Medicine*, vol 132, no. 5, p 409.

¹⁹⁹³ Quill, Timothy E and Byock, Ira R. (2000) 'Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids', *Annals of Internal Medicine*, vol 132, no. 5, p 409.

¹⁹⁹⁴ *Criminal Code Act 1899* (Qld), s 282A(1).

¹⁹⁹⁵ Queensland University of Technology, End of Life Law in Australia, Palliative Medication, <https://end-of-life.qut.edu.au/palliative-care>.

¹⁹⁹⁶ Queensland University of Technology, End of Life Law in Australia, Palliative Medication, <https://end-of-life.qut.edu.au/palliative-care>.

*provided to ensure that the statutory defence cannot be abused, either by a proeuthanasia doctor, or by a doctor with more sinister intentions.*¹⁹⁹⁷

According to White, Willmott and Ashby (2011):

*Ethics, public policy and the law have all given strong support to the need to control pain, retain dignity and avoid futile and burdensome treatment for people who are dying, provided that death is not intentionally caused in the process. The so-called principle, rule or doctrine of double effect, derived from the tradition of Catholic moral theology, offers a bioethical technique that can be used to make a distinction between lawful palliative care interventions and euthanasia (in jurisdictions...where this is illegal).*¹⁹⁹⁸

The doctrine, applied to palliative care, is generally accepted in the medical profession and its peak bodies, although some dispute its relevance on the basis that properly administered palliative care does not hasten death.¹⁹⁹⁹

White, Willmott and Ashby (2011) further state in relation to the hastening of death through palliative medication:

*...the experience of the hospice and palliative care movement over the past three decades has shown that the safe and effective use of morphine, other opioids, and sedatives in pain and symptom control need not bring cause of death into question. There is no clinical scientific evidence that morphine causes death, if used with appropriate skill to treat symptoms. In particular, the respiratory depressant effects have been shown to be minimal, and it seems that the presence of pain acts as antagonist to respiratory depression and sedative effects of opioids. However, like any class of drugs, the opioids are dangerous if used inappropriately...It should be acknowledged by practitioners that, as death approaches, abatement of life-sustaining treatment and terminal sedation may indeed alter the time of death, although this matter cannot be verified scientifically, one way or the other, in a particular case, or in general. There are serious limitations to the use of clinical studies in this area, and the causal question itself cannot be directly asked in any interventional study for obvious reasons. We cannot know when a particular patient would have died in the absence of palliative interventions or treatment abatement, particularly during the final dying process, and it would be unethical to design randomised controlled trials to find out.*²⁰⁰⁰

21.3.3 Stakeholder views on palliative sedation

21.3.3.1 Palliative sedation and hastening of death

The committee heard a range of views about the role of palliative sedation (or terminal sedation), particularly in relation to the line between relieving suffering and hastening death.

Dr Phillip Good, a Palliative Medicine Specialist at St Vincent's Private Hospital and Mater Health Services in Brisbane, told the committee:

There is this idea that drugs that are used in palliative care somehow shorten someone's life which is just not true at all. All the research, including research by people in Australia—I have

¹⁹⁹⁷ McGhee, Andrew (2004) 'Double Effect in the Criminal Code 1899 (QLD): A Critical Appraisal', *QUT Law and Justice Journal*, Vol 4, No. 1, p 49.

¹⁹⁹⁸ White, Benjamin P, Willmott, Lindy and Ashby, Michael (2011) 'Palliative care, double effect and the law in Australia', *Internal Medicine Journal*, vol. 41, no. 6, p 2.

¹⁹⁹⁹ White, Benjamin P, Willmott, Lindy and Ashby, Michael (2011) 'Palliative care, double effect and the law in Australia', *Internal Medicine Journal*, vol. 41, no. 6, pp 2-3.

²⁰⁰⁰ White, Benjamin P, Willmott, Lindy and Ashby, Michael (2011) 'Palliative care, double effect and the law in Australia', *Internal Medicine Journal*, vol. 41, no. 6, p 4.

*done research on that— is that the use of medications in palliative care, used within clear clinical guidelines, does not shorten anyone's life.*²⁰⁰¹

And:

*For most people when we are talking about using sedation for refractory distress we are talking about using medication right at the end of life, in the last hours of life, occasionally the last days of life, but certainly not in the last weeks or months of life. We are not talking about somehow someone's life is a very long period and it becoming a very short period. The really important thing is that that medication is used when people are dying. There is nothing that is going to stop the dying process at that stage. Medication is not going to shorten the process. Medication is aimed to help with the distress.*²⁰⁰²

Dr Good clarified the differences between palliative medicines and drugs used in connection with euthanasia and VAD:

*...the drugs used in both situations are very different. To give you an example, for sedation we use drugs like morphine and Valium type drugs, but people do not use that for euthanasia or voluntary assisted dying because they do not work. They do not actually work in that situation, so they are not the drugs used. Initially, many years ago when it first came into places like the Netherlands, they did try to use the drugs that we use in palliative care, but people did not die, so they stopped using them and they use different drugs now which we do not really use in palliative care from that point of view.*²⁰⁰³

Dr Chris Moy, Chair of the Australian Medical Association Ethics and Medico-Legal Committee told the committee that the patient passing is a potential side effect that is within the realms of the concept of double effect. He stated:

Ultimately, with palliative care the intention is to maintain the comfort and dignity of the individual; with euthanasia the intention is to end life—assisted dying. The only difference is the medications provided to the patient. It is down to intention.

...

*As long as my intention is to continue to maintain the comfort and dignity of the individual—and that means I give a medication dosage that I think is within the bounds that is required and I keep on escalating it in a graduated fashion until it stops the symptoms—that is palliative care. Terminal sedation as the end result is probably the ultimate in that. That is for certain groups of people where the symptoms are so great that the individual is unconscious. They are put in a state where their symptoms are so great that they need to be held in a position where they cannot respond and they will not be responding—much like anaesthetic. That fits within the gamut of palliative care.*²⁰⁰⁴

Dr Dilip Dhupelia, President of the Australian Medical Association Queensland Branch (AMA Queensland) referred in his evidence to the importance of managing dosage levels to achieving palliative sedation:

In the sedation, if we are giving morphine, for example, we start at 10 milligrams and see what the response is. If it is no, not good enough, we go to 20, go to 30, go to 40, go to 50. If I want to actually kill that person then why would I not just go straight for 100 milligrams because I know that will actually do that? There is a difference between titrating the dose to put them into a comfortable state and actually giving a lethal dose. The intention here is to actually put them

²⁰⁰¹ Public hearing, Brisbane, 5 April 2019, pp 6-7.

²⁰⁰² Public hearing, Brisbane, 5 April 2019, p 7.

²⁰⁰³ Public hearing transcript, Brisbane, 5 April 2019, p 7.

²⁰⁰⁴ Public hearing transcript, Brisbane, 4 July 2019, p 31.

*into terminal sedation, the intention is not to actually give them a dose that will actually knock them off.*²⁰⁰⁵

In their submission, Health Professionals Say No! refuted the belief that morphine hastens the death of a patient:

Very occasionally in the terminal stages of disease the distressing nature of a patient's symptoms may require the careful sedation of the patient, while seeking to preserve their dignity. It is not euthanasia because the intention is not to kill the patient, but to alleviate their distressing symptoms.

Some people would call this practice of symptom control passive euthanasia because of a myth in the community that use of morphine shortens the life of the patient. They argue that if we already practice that type of euthanasia, there is no reason not to practice the other type of euthanasia, using lethal injection, which they call active euthanasia. You see the problem in this terminology. We therefore suggest that the terms 'active' and 'passive' euthanasia be avoided.

*Philosophers have spent a lot of time talking about the principle of double effect in order to justify analgesia use at the end of life, but it really isn't necessary. It's all based on a myth – that morphine kills the patient. This myth [has] been around for years, and we don't seem to be able to squash it. It makes people scared to use what is an excellent treatment for pain. But in fact morphine in therapeutic doses does not shorten life. Indeed, it may actually prolong it. An Australian study showed increased survival of palliative care patients on high doses of morphine, likely due to a less stressful and better symptomatically controlled dying process for those individuals.*²⁰⁰⁶

21.3.3.2 Patient choice

The issue of patient choice was raised in the discussion on palliative sedation. Dr Heather McNamee stated at a hearing in Brisbane 'one of my objections to this practice is that by that stage of dying the process is in the hands of the family and the doctor and the decisions are not being made by the patients themselves'.²⁰⁰⁷ Similarly, Mr David Muir from the Clem Jones Trust referred to palliative sedation involving the intent of the doctor or medical staff, not the rational adult patient who wants to control their death.²⁰⁰⁸

At a public hearing in Brisbane, Dr Luc Deliens, Director of the End-of-Life Care Research Group and Professor of Palliative Care Research, Vrije Universiteit Brussel & Ghent University, Belgium told the committee:

*The problem is that it is very often also a practice without the consent of the patients, while euthanasia can be practised with the full consent and explicit request of the patients. It is not a practice that is only the patient's choice. It is not the patient's autonomous choice—palliative sedation. It is very often practised because there are clinical circumstances that need it.*²⁰⁰⁹

21.3.3.3 Lack of safeguards

A number of submissions highlighted the absence of guidelines for palliative sedation in Australia.

The Clem Jones Group suggested that the doctrine of double effect:

...exists with no legal framework, protections for the vulnerable, and no legislated criteria for eligibility or oversight and penalties for misapplication. In some circumstances it may also be

²⁰⁰⁵ Public hearing transcript, Brisbane, 4 July 2019, p 38.

²⁰⁰⁶ Submission 1265, pp 12-13.

²⁰⁰⁷ Public hearing transcript, Brisbane, 23 August 2019, p 43.

²⁰⁰⁸ Public hearing transcript, Brisbane, 23 August 2019, p 3.

²⁰⁰⁹ Public hearing transcript, Brisbane, 21 October 2019, p 5.

*applied unfairly and may be dependent on an individual or their family members knowing how to frame a request for such a procedure when talking to medical practitioners.*²⁰¹⁰

Dr Heather McNamee also referred to a lack of safeguards, stating ‘as this process is done unofficially, there are no safeguards to monitor the decisions of the doctors or the family, which could mean inappropriate practices would effectively be covered up’.²⁰¹¹

21.4 When symptoms cannot be controlled: patient options

As highlighted in section 21.2, sometimes palliative care does not sufficiently relieve a patient’s symptoms. This sections discusses the rights of individuals to refuse sustenance, hydration and medical treatment. It also exposes the limitations of advance directions about future medical treatments at the end of their life where patients have lost cognitive capacity.²⁰¹²

Patients are currently unable to access Voluntary Assisted Dying in Queensland. Although modern medicine recognises the principle of the autonomy of the patient, the options available to patients under these circumstances are somewhat limited. The following sections explain what these lawful options are. They include:

- refusal of medical treatment, and
- refusal of food and/or hydration.

In some cases the options to refuse medical treatment, or to refuse food and hydration are further complicated by the laws relating to loss of capacity.

21.4.1 Refusal of medical treatment

For medical treatment to be lawful, a person must consent to the treatment unless it is provided in an emergency in order to save the person’s life and it is not possible to obtain consent from the person or their substitute decision-maker.²⁰¹³

An adult can give their consent to accept or refuse medical treatment if they:

- understand the doctor’s information about the treatment,²⁰¹⁴ and
- can make reasonable choices based on this information.²⁰¹⁵

The consent must be given freely and voluntarily, and it must relate to the proposed treatment.²⁰¹⁶

²⁰¹⁰ Submission 1202, p 24.

²⁰¹¹ Public hearing transcript, Brisbane, 23 August 2019, p 43.

²⁰¹² ‘Capacity’ is a person’s ability to: understand the nature and effect of decisions; freely and voluntarily make decisions; and communicate those decisions in some way. For more information, see Queensland Health, *Your rights at the end of life – ‘Capacity’*, <https://www.qld.gov.au/health/support/end-of-life/advance-care-planning/legal/capacity>.

²⁰¹³ Queensland University of Technology, End of Life Law in Australia, Legal Overview, <https://end-of-life.qut.edu.au/legal-overview>.

²⁰¹⁴ According to the Queensland Law Handbook, before a person can consent to or refuse particular medical treatment, they need to have a reasonable understanding of what that treatment involves. The treating health practitioner is required to provide a proper explanation of the medical treatment and the risks involved. A health professional has a duty to warn a patient of a material risk inherent in proposed treatment.

²⁰¹⁵ Queensland Government, *Your rights at the end of life, Consent*, <https://www.qld.gov.au/health/support/end-of-life/advance-care-planning/legal/consent>.

²⁰¹⁶ Queensland University of Technology, End of Life Law in Australia, Legal Overview, <https://end-of-life.qut.edu.au/legal-overview>.

If a patient with capacity refuses medical treatment, a clinician (or whoever provides care) may be civilly and criminally liable, and may be charged with assault, if they were to provide treatment against the patient's wishes. This forced treatment could also provide grounds for disciplinary action against the clinician or other health service provider through the Australian Health Practitioner Regulation Agency (AHPRA) and/or the Health Ombudsman.²⁰¹⁷

The courts have recognised that adults have the right to specify in advance that they wish to refuse treatment if they lose capacity in the future—even if this results in their death or would cause it to happen sooner.²⁰¹⁸ This is not considered to be suicide, but rather the person exercising his or her right to refuse treatment.²⁰¹⁹

If a person lacks capacity to give consent, someone else must make decisions on their behalf. If a person has impaired capacity, consent must be obtained through the following (in order of priority), except in some emergency situations:

1. a valid Advance Health Directive
2. a guardian appointed by the Queensland Civil and Administrative Tribunal
3. a health attorney under an Advance Health Directive or Enduring Power of Attorney
4. a statutory health attorney(s)
5. the Public Guardian.²⁰²⁰

As described in section 20.3.1 an AHD, sometimes called a living will, is a formal way to give instructions about future health care. It comes into effect only if a patient's cognitive health deteriorates and they become unable to make decisions (i.e. lose capacity to make decisions).²⁰²¹ In Queensland, AHDs are made in accordance with the *Powers of Attorney Act 1998* (Powers of Attorney Act) and must meet the requirements set out in that Act to be valid.

In circumstances where the direction in an AHD is to withdraw life-sustaining treatment, s36(2) of the Powers of Attorney Act states that such a direction in an AHD cannot operate unless certain conditions apply. The patient's medical condition must fall within one of following four categories,

- the patient has a condition that is incurable or irreversible and may reasonably be expected to die within one year,

²⁰¹⁷ Queensland Health, *End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients*, January 2018, pp 103-104.
https://www.health.qld.gov.au/__data/assets/pdf_file/0026/813392/qh-gdl-462-2019.pdf; <https://end-of-life.qut.edu.au/legal-overview>.

²⁰¹⁸ The Guardianship and Administration Act 2000 (Qld) acknowledges that an adult's right to make decisions is fundamental to their inherent dignity. The Act also acknowledges an adult's right to make decisions with which others may not agree. A patient with capacity has the right to refuse any medical treatment, including palliative care, while they have capacity. A patient with a life-limiting illness may, for instance, refuse all active treatments and choose to return to their home to die, comforted and supported by loved ones and palliative care professionals. The wishes of a patient must be followed while the patient has capacity.
 Queensland Health, *End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients*, January 2018, p 104.
https://www.health.qld.gov.au/__data/assets/pdf_file/0026/813392/qh-gdl-462-2019.pdf.

²⁰¹⁹ Queensland University of Technology, *End of Life Law in Australia, Euthanasia and Assisted Dying*,
<https://end-of-life.qut.edu.au/euthanasia>.

²⁰²⁰ Queensland Government, *Your rights at the end of life, Consent*,
<https://www.qld.gov.au/health/support/end-of-life/advance-care-planning/legal/consent>.

²⁰²¹ Queensland Government, 2020, 'Advance health directive'. <http://www.https://www.qld.gov.au/law/legal-mediation-and-justice-of-the-peace/power-of-attorney-and-making-decisions-for-others/advance-health-directive>.

- the patient is in a persistent vegetative state with irreversible brain damage,
- the patient is permanently unconscious, or
- there is no prospect that the patient will recover.²⁰²²

If one of those conditions listed apply, then the direction in an AHD is also subject to the following criteria:

- for a direction to withhold or withdraw artificial nutrition or artificial hydration—the commencement or continuation of the measure would be inconsistent with good medical practice (section 36(2)(b)); and
- the adult has no reasonable prospect of regaining capacity for health matters (section 36(2)(c)).²⁰²³

In its review of Queensland’s guardianship laws in 2010, the Queensland Law Reform Commission recommended that s36(2) of the Powers of Attorney Act be omitted.²⁰²⁴ This would remove the restriction the Act places on a patient’s autonomy, and a direction made in an AHD to withdraw life sustaining treatment would be followed. At the time of writing, S36(2) remains part of Queensland law.

The committee sought advice from the Department of Justice and Attorney General on the status of the Commission’s recommendations. In its correspondence with the committee, the department advised that it is not currently reviewing the operation of S36(2) of the Powers of Attorney Act. The department did not provide reasons for not implementing the QLRC recommendation and further noted that it was a matter for the government to consider.²⁰²⁵

21.4.1.1 Stakeholder views on refusal of medical treatment

The Australian Lawyers Alliance noted in their submission how the principle of autonomy and its role in a person’s medical treatment is a fundamental part of Australia’s common law with healthcare providers:

*In recent times, Australian healthcare has been strongly influenced by the principle of patient autonomy i.e. a patient’s right to direct their own healthcare. This principle is a fundamental part of Australia’s common law with healthcare providers obligated to obtain consent from their patients prior to providing treatment. In the context of withdrawing and/or withholding life-sustaining treatment, it is now uncontroversial at law that a competent patient can refuse life-sustaining treatment even if such a refusal will result in the death of that patient. This is because for a competent patient the principle of autonomy takes precedence if it conflicts with the value of human life.*²⁰²⁶

Specialist in emergency medicine, Dr Bill Lukin explained the complexities doctors face providing patient with emergency and other care that accords with their wishes:

You can make a direction about your future health care in an advance health directive and I can override it as a doctor if I think it is not in keeping with good medical practice, which takes a right away from you that you had as a competent person. I cannot make a change to what your wishes are just because I think it is a bad idea. Understanding the law really well helps when you are

²⁰²² Powers of Attorney Act 1998, S36(2)(a)

²⁰²³ Powers of Attorney Act 1998, S36(2)(b), S36(2)(c).

²⁰²⁴ Queensland Law Reform Commission 2010, A review of Queensland's Guardianship Laws, 2010, Executive Summary, p xii, <https://www.qlrc.qld.gov.au/publications>.

²⁰²⁵ Department of Justice and the Attorney-General, correspondence dated 19 February 2020, attachment p 6.

²⁰²⁶ Submission 1204, p 5.

*resuscitating people. It is really important that you can say to people, 'I know this is not euthanasia. You are allowed to not have treatment. It is okay. We can make you comfortable'.*²⁰²⁷

Professor Lindy Willmott in her evidence noted the difficulties caused by excessive restrictions in the Powers of Attorney Act that allow doctors to ignore patients' explicit directions made in their AHDs:

*The current legislative regime is not working well in that there are too many restrictions which may mean that, where a person is trying to refuse treatment, an advance health directive will not operate. There are restrictions in sections 36 and 103 of the Powers of Attorney Act that allow doctors to disregard it if it is inconsistent with good medical practice. I do think it is in urgent need of change. I also agree that if the Queensland system acknowledged common law advance health directives that would address some of those concerns as well.*²⁰²⁸

In contrast, Mr David Muir of the Clem Jones Trust argued that there was an absence of safeguards for people at the end of their life under existing laws submitting:

*...when it comes to the refusal of treatment, there are no safeguards against pressure being applied by family members or others who may be motivated by personal gain to see the life of their relative end. There is no legal scaffolding around these options similar to the legislated safeguards and protections in voluntary assisted dying laws in other jurisdictions to protect the dying person, medical professionals, or others around them.*²⁰²⁹

21.4.2 Refusal of food and hydration

Voluntarily stopping eating and drinking (VSED) or voluntary palliated starvation (VPS) occurs when an adult with capacity refuses both artificial nutrition and hydration (for example, given through a tube into the person's stomach) and ordinary food and drink, and receives palliative care to relieve any suffering she or he experiences from dying due to a lack of food (nutrition) and water (hydration). Some patients may refuse hydration and nutrition as an alternative to physician-assisted suicide.²⁰³⁰

The legal status of VPS is arguably unclear, particularly in relation to issues such as whether the person's substitute decision-maker can continue to refuse food and drink for the person once they lose capacity, and whether a person can make a binding AHD refusing food and drink. Under Australian common law, patients have the right to refuse food and drink, even if it results in death.²⁰³¹ In *H Ltd v J*, Kourakis J stated:

*I find that refusal of sustenance and medication is not suicide within the common law meaning of that term.*²⁰³²

White, Willmott and Savulescu (2014) note that in some circumstances a death resulting from a competent patient's decision to cease eating and drinking may be lawful for both the patient and doctors involved, and it can be lawful and ethical to provide palliative care to reduce the suffering associated with VSED.²⁰³³

²⁰²⁷ Public hearing transcript, Brisbane, 6 February 2019, p 14.

²⁰²⁸ Public hearing transcript, Brisbane, 5 Jul 2019, p 10.

²⁰²⁹ Submission 1202, p 13.

²⁰³⁰ Queensland University of Technology, End of Life Law in Australia, Palliative Medication, <https://end-of-life.qut.edu.au/palliative-care>.

²⁰³¹ Queensland University of Technology, End of Life Law in Australia, Palliative Medication, <https://end-of-life.qut.edu.au/palliative-care>.

²⁰³² *H Ltd v J* (2010), 107 SASR 352.

²⁰³³ White, Benjamin P., Willmott, Lindy, & Savulescu, Julian, Voluntary palliated starvation : A lawful and ethical way to die? *Journal of Law and Medicine*, (2014) 22, pp. 376-386,

However, in circumstances where a person has lost capacity the law around VSED is more complex. As mentioned in the previous section on refusal of medical treatment, a direction in an AHD to withdraw or withhold artificial nutrition and hydration, will only operate where a person has one of the four conditions listed and in circumstances where the treating doctor considers it good medical practice.²⁰³⁴

21.4.2.1 Stakeholder views on refusal of food and hydration

At the Townsville public hearing, palliative care physician, Dr Will Cairns explained the difference between VSED and the stopping of eating and drinking because a person is dying and feels neither hunger or thirst:

*...those who voluntarily decide not to eat or drink and then they die because, while physiologically feeling hungry or thirsty, they have decided not to and just closed up shop. I would imagine they are more likely to die from distressing symptoms. On the other side of the coin are those people who stop eating and drinking because they are dying. As clinicians we have all seen patients who are approaching the end of their life, say with cancer, and they lose their appetite and they are not interested in drinking very much and they deteriorate and they are not usually distressed by the not eating or drinking because, as I have said to family members on many occasions, they are not dying because they are not eating or drinking; they are not eating or drinking because they are dying. On the other hand, someone who voluntarily stops eating or drinking in order to die is dying because they are not eating or drinking.*²⁰³⁵

A number of witnesses shared with the committee the personal, direct experiences supporting loved ones who chose to end their lives this way in the absence of alternatives. Mr David Muir of the Clem Jones Group told the committee that a 'significant numbers of Queenslanders are dying of starvation and dehydration because the only option for them now is to refuse food and water to hasten death'.²⁰³⁶

Ms Moya Jackson shared her experiences from the death of her brother Earl in 2018 while suffering from cancer:

...my brother Earl was diagnosed with cancer in late 2017. He had to take the only choice that was available to him and he starved himself of food and water from February until his death on 25 March last year. His wish to be gone was known to all. ... We were devastated to see him in so much pain, and pain that could not be alleviated. His oncologist was devastated watching him and his pain. His body reacted violently, expelling foul fluids regularly, necessitating his bedding being changed frequently. He was devastated the condition his own body was in. His death was gruesome and undignified, and I will forever be haunted by the sight of his deterioration. He was a skeleton. He looked like someone who walked out of a concentration camp.

We are all going to die someday—that is a given—but it should never look like this. Palliative care has a place, but it should not be the only option available. We respect those who disagree, but please remember that voluntary assisted dying is a choice; it is not mandatory. People considering VAD have used every method possible to stay alive. Please respect those choices. People who do not believe it is the right thing to do not need to take that option. If it is against religion to access VAD, do not take that option. Do not tell me, though, that because it is against

https://eprints.qut.edu.au/79897/9/_staffhome.qut.edu.au_staffgroupc%24_carstens_Desktop_Voluntary%2520palliative%2520starvation%2520%28submitted%2520to%2520JLM%2520-%2520eprints%29%5B1%5D.pdf.

²⁰³⁴ Powers of Attorney Act 1998, S36(2).

²⁰³⁵ Public hearing transcript, Townsville, 29 May 2019, p 10.

²⁰³⁶ Public hearing transcript, Brisbane, 23 August 2019, p 3.

*your religion I should not have that choice. Voluntary assisted dying does not mean more people dying; it simply means less people suffering.*²⁰³⁷

Ms Lyn Morgan, shared experiences at the Rockhampton public hearing about the passing of her friend over four days following withdrawal of food, water and medical treatment.

*When she was told there was nothing they could do she asked, 'Well, how can I die?', and they only gave her the option of withdrawing food, water and medical treatment and my friend elected to do that. I sat with her for four days watching her cry out in pain and she literally starved and thirsted to death, which was the only way she could hasten her death.*²⁰³⁸

Mr Alan Roughan told the committee of the passing of his late wife Jill who had battled Parkinson's Disease for seven years. Jill died over four days after she stopped taking food and water, despite having an AHD in place:

When Jill's refluxing became uncontrollable due to aspirating fluids coming into her lungs, we went to the Esk Hospital, where she was ably fitted with a morphine pump to try to stop the spasms and relieve any anxiety. Jill had indicated to me by prearranged signals that she had absolutely had enough, so we returned home. Unfortunately, the advance health directive allows only withdrawal of medications, food and fluids, so it took four more days to virtually starve her to death. She had such a strong heart.

...

*Palliative care is fine, but it has its limitations in these circumstances.*²⁰³⁹

Similarly, Ms Sharon Kelly wrote to the committee about the death of her father:

*Dad's last month was spent refusing food or nourishment. This course of action meant that his last weeks were painful and miserable. It was terrible that his only 3 grandchildren had to see their Grandad suffer. Sadly this Queensland Government enquiry has come too late for him.*²⁰⁴⁰

Mrs Laurel Beale told the committee about the passing of her late husband over four days after ceasing to take food and water, which she described as 'starving to death':

We chose palliative care over the nursing home. To be honest, I did not even know what palliative care was. I soon understood that when a person has no future quality of life he could be medically assisted to end his life. He would be kept comfortable with drugs, but the very basics of life—food and water—were withheld until he passed away. Straightaway I thought, 'He's going to be starved to death.'

*Palliative care was to become our reality. To be honest, it was soul destroying. It was not a pretty sight for any of the family. We believe that he was still in a little bit of pain. For six days and nights we all sat with Neil while this amazing man slowly let go of life. He was given no food or water, but was given small doses of fentanyl for pain relief and other drugs to dry up his body fluids and to assist with any anxiety he may suffer. From our perspective, as I said, he was basically starving to death.*²⁰⁴¹

For example, Ms Raeleen Young, a resident of Victoria, told the story of her 25 year old son who had Duchenne Muscular Dystrophy, and after refusing food and water, took four days to pass:

²⁰³⁷ Public hearing transcript, Bundaberg, 16 July 2019, p 16-17.

²⁰³⁸ Public hearing transcript, Rockhampton, 17 July 2019, p 18.

²⁰³⁹ Public hearing transcript, Toowoomba, 17 May 2019, p 16.

²⁰⁴⁰ Submission E266, p 1.

²⁰⁴¹ Public hearing transcript, Brisbane, 13 September 2019, p 52.

*...on Monday 7th January 2019 he made the difficult decision to refuse food & water, wanting to go out on his own terms after a long & courageous battle. We nursed him at home until he passed in our arms at 4:12am Friday 11th January 2019. No human being should ever feel they have no other choice but to allow their body to starve & dehydrate.*²⁰⁴²

In contrast, Mr Andrew Harms shared the tragic story of the passing of his father who took seventeen days to pass:

Dad got ill and got taken to hospital ... the doctor said, 'There's two options. We can treat him.' He had septicaemia in the blood - I think that is what it is called—or blood poisoning. They said, 'He will not live, but we can treat it and it may prolong his life,' or we could say, 'That's enough,' and it is called nil by mouth. They said that generally they live between three hours and three days. That is usually the time frame. We were there for 17 days with this man who had not had one thing in his body except morphine.

*The reason I am here today is that we made that decision that he was going to pass, but to go through that process of 17 days with the family was absolutely horrendous. ... My question, I suppose, is: the decision was made there that he would not be coming back. I have never heard of anyone go, 'We're going to change our mind and we're going to start giving them water and food and medication.' Surely that process can be different rather than nil by mouth.*²⁰⁴³

21.5 Providing effective palliative care: constraints on health professionals

21.5.1 Is the current law complicating the work of health professionals?

During the inquiry hearings, several health professionals commented on the impact on medical decision making of the complicated legal framework that operates in circumstances where a patient has lost capacity.

Dr Chris Moy, Chair of the Australian Medical Association Ethics and Medico-Legal Committee and President of the Australian Medical Association South Australia, advised the committee that problems arise when the law is complicated.

*I have been involved with the GP Palliative Shared Care Program in South Australia and the development of the South Australian advance care directive legislation. A lot of the confusion is about what you are trying to do in palliative care. To be frank, it cannot be complicated, because if it is complicated then in the middle of the night when you have to make this decision, or when you are running around at lunchtime trying to make end-of-life decisions, you get a problem.*²⁰⁴⁴

He provided this example to the committee:

*Currently, if they were to have pneumonia, were dying from pneumonia and needed antibiotics but the substitute decision-maker says, 'Don't give them antibiotics because she's happy to pass away and that is her wish,' that should be allowed. That is not euthanasia. That is palliative care. What can happen now is a doctor can override that, because it is in their best interests. You have very strange legislation in Queensland and I think you need to sort that out first.*²⁰⁴⁵

Dr Moy provided the committee with a copy of the Queensland Health *End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients*. That

²⁰⁴² Submission 161, p 1.

²⁰⁴³ Public hearing transcript, Mossman, 28 May 2019, p 10-11.

²⁰⁴⁴ Public hearing transcript, Brisbane, 4 Jul 2019, p 31.

²⁰⁴⁵ Public hearing transcript, Brisbane, 4 Jul 2019, p 33.

176-page reference document provides guidelines to assist health professionals in decision-making around life-sustaining measures.²⁰⁴⁶ Dr Moy further commented:

*Because of your rather confusing legislation, these are decisions that have to be made sometimes at lunchtime when I am running down there. That is why we are saying that you need to sort out your legislation first before you start thinking about voluntary assisted dying. Currently, doctors are all at sea to some degree because they cannot make a proper decision. Your patients do not have proper autonomy.*²⁰⁴⁷

Some of the complexities around end-of-life decision making involve consent to treatment where a patient has lost capacity and the withdrawal or withholding of life sustaining treatment where the treatment is futile.

21.5.2 Providing treatment where a person has lost capacity

A person has the right to consent to or refuse treatment based on the principle of personal autonomy.²⁰⁴⁸ The courts have also recognised that adults have the right to say in advance that they want to refuse treatment if they lose capacity in the future—even if this results in their death or would cause it to happen sooner.²⁰⁴⁹ As discussed in section 21.4.1, a direction in an AHD may not operate in some circumstances. In his evidence to the committee, Dr Lukin advised of the issues and complexities when providing treatment to patients who had lost capacity. He explained that recent changes in the Guardianship laws had the effect of clinicians having to seek the consent of patients' families to withhold treatment in cases where the patient was incapacitated:

... the most recent iteration of the Guardianship and Administration Act, where withdrawing and withholding life-sustaining treatment was deemed to be treatment. This is where the doctors do not understand it and a lot of the distress in the hospital is driven. Previously, withdrawing and withholding life-sustaining treatment in the Guardianship and Administration Act was under 'special health care' because you needed a tribunal decision for special health care. In that, one of the options was the cessation of dialysis. You could not withdraw dialysis from a patient without going to the tribunal.

Then when the law was rewritten, we realised that we withdraw and withhold life-sustaining treatment all the time from patients. Patients make decisions and families make decisions to withdraw and withhold life-sustaining treatment. If the patient is not competent there has to be a mechanism to make that decision, and we do it all the time. Every week a lot of cardiac arrests come to the Royal Brisbane, but we do not put them all onto ECMO or whiz them off to the Prince Charles for heart-lung bypass. We withdraw and withhold life-sustaining treatment all the time. They realised that it could not be in the special health care; it had to be in the general part of the act.

As part of the act, they defined withdrawing and withholding life-sustaining treatment as health care. In the act it says, 'For the purposes of the act, withdrawing and withholding life-sustaining treatment is considered to be treatment,' so you need consent to do it. All of a sudden, we needed consent from patients' families who were not competent to withdraw and withhold life-

²⁰⁴⁶ Queensland Health, *End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients*, 2018, https://www.health.qld.gov.au/__data/assets/pdf_file/0033/688263/acp-guidance.pdf.

²⁰⁴⁷ Public hearing transcript, Brisbane, 4 Jul 2019, p 33.

²⁰⁴⁸ Queensland Health, *End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients*, January 2018, p 104. https://www.health.qld.gov.au/__data/assets/pdf_file/0026/813392/qh-gdl-462-2019.pdf.

²⁰⁴⁹ Queensland Health, *End-of-life care: Guidelines for decision-making about withholding and withdrawing life-sustaining measures from adult patients*, January 2018, p 104.

*sustaining treatment. This is how complex it is. I understood it for about three weeks around my exams.*²⁰⁵⁰

21.5.3 Are health professionals required to provide medically futile treatment?

In general, doctors have no legal obligation to provide treatment that is medically futile.²⁰⁵¹ The Australian courts have indicated that, where treatment is futile, it will not be in the patient's best interests.²⁰⁵² While there is no internationally agreed definition of 'futile medical treatment', the Australian Medical Association (AMA) defines 'futile treatment' as:

*Treatment that no longer provides a benefit to a patient or treatment where the burdens of treatment outweigh the benefits. Doctors are not required to offer treatment options they consider neither medically beneficial nor clinically appropriate.*²⁰⁵³

The AMA's *Position Statement on End of Life Care and Advance Care Planning 2014* makes the following statements on medical futility:

7.1 Doctors should understand the limits of medicine in prolonging life and recognise when efforts to prolong life may not benefit the patient. In end of life care, medically futile treatment can be considered to be treatment that gives no, or an extremely small, chance of meaningful prolongation of survival and, at best, can only briefly delay the inevitable death of the patient.

7.2 Whilst doctors are generally not obliged to provide treatments that are considered medically futile, where possible it is important that the doctor discuss their reasons for determining a treatment to be medically futile with the patient (and/or the SDM [Substitute Decision Maker], carers, family members) before deciding the treatment should not be offered.

*7.3 In some cases, a treatment may not offer a benefit in terms of curing a patient's condition, or significantly extending life or improving quality of life, but it may benefit the patient in other ways. For example, a 'medically futile' treatment may briefly extend the life of the patient so he or she can achieve their wish of saying goodbye to a relative who is arriving shortly from overseas.*²⁰⁵⁴

In most states in Australia a doctor may unilaterally decide not to provide treatment that is futile.²⁰⁵⁵ However, in Queensland, when the patient has impaired capacity, there is an exception to this rule.²⁰⁵⁶ Where a person has impaired capacity, and the treatment is the withdrawal or withholding of a life-sustaining measure, the doctor requires consent from that person's substitute decision-maker (for example, a person with an Enduring Power of Attorney, the Public Guardian, or a statutory health

²⁰⁵⁰ Private briefing, Brisbane, 6 December 2018, p 13.

²⁰⁵¹ *Airedale NHS Trust v Bland* [1993] 1 All ER 821.

²⁰⁵² Willmott, Lindy; White, Ben; & Smith, Malcolm K, "Best interests" and withholding and withdrawing life-sustaining treatment from an adult who lacks capacity in the parens patriae jurisdiction, *Journal of Law and Medicine* (2014) 12(4), p 925, <https://eprints.qut.edu.au/73554/6/73554.pdf>.

²⁰⁵³ Australian Medical Association, *Position Statement on End of Life Care and Advance Care Planning 2014*, https://ama.com.au/system/tdf/documents/AMA_position_statement_on_end_of_life_care_and_advance_care_planning_2014.pdf?file=1&type=node&id=40573. This definition is based on the Clinical, Technical, and Ethical Principal Committee of the Australian Health Ministers' Advisory Council's document *A National Framework for Advance Care Directives* from September 2011.

²⁰⁵⁴ Australian Medical Association, *Position Statement on End of Life Care and Advance Care Planning 2014*.

²⁰⁵⁵ Willmott, Lindy; White, Benjamin P.; & Downie, Jocelyn, Withholding and withdrawal of 'futile' life-sustaining treatment: unilateral medical decision-making in Australia and New Zealand. *Journal of Law and Medicine*, (2013) 20(4), p. 915.

²⁰⁵⁶ A clinician who provides health care (including withholding or withdrawing treatment) without consent commits an offence. *Guardianship and Administration Act 2000* (Qld), s 79.

attorney) even if that treatment is futile or non-beneficial.²⁰⁵⁷ In those circumstances, consent by a substitute decision-maker would only operate where the withholding or withdrawal of a life-sustaining measure is consistent with good medical practice.²⁰⁵⁸ In Queensland, clinicians who provide healthcare without consent commit an offence pursuant to s 79 of the *Guardianship and Administration Act 2000*.

If the substitute decision maker does not consent to the withdrawal or withholding of the futile treatment, then the Public Guardian, the Queensland Civil and Administrative Tribunal (QCAT) or the Supreme Court can authorise it if it is in the patient's best interests.²⁰⁵⁹

21.5.3.1 *Views of Health Professionals about futile medical treatment*

A number of peak medical bodies commented on futile treatment. Dr Bruce Willett, Chair of the Royal Australian College of General Practitioners Queensland, told the committee that avoiding futile medical treatment and reducing the burden on patients and the medical system is something that general practitioners are mindful of:

*To see resources diverted away from that sort of treatment into more practical community support—these people often do not need their cholesterol medication, they need the community nurse—would be a far better use of those funds. I think we would all agree on that.*²⁰⁶⁰

Similarly, Dr Anthony Herbert, Director of the Paediatric Palliative Care Service (PPCS) at the Queensland Children's Hospital (part of the Children's Health Queensland Hospital and Health Service), told the committee:

*Good paediatrics would confer doctors should not prescribe non-beneficial and/or burdensome treatment. With-holding treatments that are non-beneficial and not going to benefit a patient, and possibly even cause them more suffering, is good medicine and should not be confused with euthanasia. For younger children, or those with developmental disability, parents will act as proxy decision makers for difficult medical decisions relating to life-prolonging medical interventions (such as intubation and mechanical ventilation).*²⁰⁶¹

In his statement to the committee, Dr Dilip Dhupelia, the President of the Australian Medical Association in Queensland, made the following recommendation in relation to futile medical treatment:

*Today I will be strongly advocating for the Queensland government to make the changes that the AMA recommends to truly support good end-of-life care for patients and the community ... legislative change so that doctors do not have to provide treatment of no medical benefit—that is, futile care—so that doctors can make end-of-life decisions for patients that are consistent with good medical practice.*²⁰⁶²

21.5.4 Are patients suffering because medical professionals fear legal sanctions?

A number of submitters told the committee that they believed doctors were under-prescribing pain medication for patients at end-of-life because of a fear of prosecution.²⁰⁶³ According to a focus group

²⁰⁵⁷ Willmott, Lindy, White, Benjamin P., & Downie, Jocelyn, Withholding and withdrawal of 'futile' life-sustaining treatment: unilateral medical decision-making in Australia and New Zealand. *Journal of Law and Medicine*, (2013) 20(4), p 917.

²⁰⁵⁸ Guardianship and Administration Act 2000 (Qld), s 66A (2).

²⁰⁵⁹ Willmott, Lindy; White, Benjamin P.; & Downie, Jocelyn, Withholding and withdrawal of 'futile' life-sustaining treatment: unilateral medical decision-making in Australia and New Zealand. *Journal of Law and Medicine*, (2013) 20(4), p 918.

²⁰⁶⁰ Public hearing transcript, 4 July 2019, p 7.

²⁰⁶¹ Submission 1813, attachment, p 5.

²⁰⁶² Public hearing transcript, Brisbane, 4 Jul 2019, p 30.

²⁰⁶³ See, submission, 1291, p 75; submission E1362, p 1; submission E087, p 1; and submission E1795, p 1.

study of health professionals working in end-of-life and palliative care in the UK, 'significant barriers exist to the appropriate use of opioids in end-of-life care. These barriers include concerns about giving high doses and having insufficient training in opioid use'.²⁰⁶⁴

Similarly in Australia, Mitchell et al (2019) described anecdotal reports that some practitioners were choosing to abandon end-of-life care practice 'rather than risk professional ruin should they persist in the use of any opioid therapy',²⁰⁶⁵ while other medical practitioners had an overcautious attitude to higher dose opioids. The article stated that 'outcomes for patient care could be serious'.²⁰⁶⁶

In a briefing to the committee, Dr Lukin, explained pressure on general practitioners not to prescribe opioids:

*There is a lot of pressure on the general practitioners not to prescribe opioids. The top 20 per cent of general practitioners prescribing opioids will get a letter from the PBS saying, 'You are in the top 20 per cent and we are watching you.' We have pushback in palliative care from general practitioners who want to be involved but they are getting letters saying, 'You are prescribing too many opioids.'*²⁰⁶⁷

In an article written for NewsGP,²⁰⁶⁸ Australia's Chief Medical Officer, Dr Brendan Murphy, clarified the letter he wrote to 4,800 GPs in relation to their opioid prescription practices:

GPs are at the frontline in managing people with chronic non-malignant pain and I fully appreciate the difficulty in managing these patients and meeting their complex needs. It is clear, however, that all doctors must reflect on their prescribing practices if we are to tackle the increasing incidence of harm and death from opioids in Australia.

It is for this reason that, in June 2018, I wrote to 4800 GPs who were identified as being in the top 20% of opioid prescribers in Australia – as identified through Pharmaceutical Benefits Scheme (PBS) data.

In this process, it was not possible to identify all GPs working in palliative care or prescribing for palliative care reasons. It was also not possible to identify those GPs who have a specialist pain practice or who have a specific oncology bias to their practice.

Accordingly, these letters were targeted to a broad group of GPs, many of whose opioid prescribing was entirely appropriate for their clinical case mix.

*I want to reiterate that we strongly applaud and encourage the work of GPs who are working in palliative care, cancer management and in complex pain clinics. It would be most disappointing and undesirable if any such GPs feel their opioid prescribing practice is anything other than encouraged and supported.*²⁰⁶⁹

In its submission to the committee, Go Gentle Australia commented on the findings of the 2016 Victorian Parliamentary *Inquiry into end of life choices: Final Report* that 'some health practitioners are

²⁰⁶⁴ Gardiner C, Gott M, Ingleton C, et al. Attitudes of health care professionals to opioid prescribing in end-of-life care: a qualitative focus group study. *Journal of Pain and Symptom Management* 2012; 44: 206–214.

²⁰⁶⁵ Geoffrey K Mitchell, Lindy Willmott, Ben P White, Donella Piper, David C Currow and Patsy M Yates, A perfect storm: fear of litigation for end of life care, *The Medical Journal of Australia* 2019; 210 (10), p 441.

²⁰⁶⁶ Geoffrey K Mitchell, Lindy Willmott, Ben P White, Donella Piper, David C Currow and Patsy M Yates, A perfect storm: fear of litigation for end of life care, *The Medical Journal of Australia* 2019; 210 (10), p 441.

²⁰⁶⁷ Private briefing transcripts, 6 Dec 2018, p 5.

²⁰⁶⁸ NewsGP is the RACGP's news hub, designed and developed for members, to keep you informed of news relevant to Australian general practice.

²⁰⁶⁹ newsGP, *Australia's Chief Medical Officer responds to GP questions over opioid warning letter*, 27 June 2019, p 1. <https://www1.racgp.org.au/newsgp/professional/australia-s-chief-medical-officer-responds-to-gp-q>.

uncertain about the law relating to administration of pain relief which may have the unintended effect of ending a patient's life'.²⁰⁷⁰

Go Gentle concluded:

*.. that doctors may be inhibited from ordering adequate pain relief – it only takes one complaint for a doctor to be in serious trouble. Thus, under-treatment of pain and other suffering at the end of life is common in nursing homes, hospitals and even in palliative care.*²⁰⁷¹

In his submission to the committee, Mr Ronald King argued that the laws around the medication at end-of-life need to be clarified to protect doctors:

*As a society it is important to value human life. At the end of life often the families have trouble with medical professionals, who fail to understand that the administering of strong pain relief for a critically injured or terminally ill person is not euthanasia. If death is hastened it is not the intention, pain relief is the intention. Clarifying laws around this would protect doctors and so all of the medical profession would be willing to administer such pain relief. The Government needs to provide palliative care for all those who need it, not to treat this issue as an economic problem. People are affected by what they have witnessed in their own lives, so if a medical professional is afraid of losing their license, because they don't understand the difference between euthanasia and palliative care or have adequate protection by the law, then some doctors and medical professionals refuse to administer or prescribe the necessary administration of strong pain relief as it may unintentionally hasten death. This was our experience with my wife's uncle. I have also experienced excellent palliative care for my mother. Thanks to Prince Charles Hospital. As a result I understand the humanity of good palliative care.*²⁰⁷²

Ms Cyal Moriarty who works as a nurse in a RACF shared her concerns about patients' suffering due to the under-prescription of medication:

There is always an argument against euthanasia that is "good palliative care" that alleviate the symptoms of an end-stage disease. I counter-point that, many RACFs, one or two doctors available is a regular GP or a Locum GP that is managing the end of life care of a resident. These GPs under prescribe palliative care medications for end of life treatment plan. As they felt, "they" do not want to be responsible for prematurely ending their life. People have suffered greatly in their process of dying due to under-prescribing palliative care.

Now many private RACFs do not have the same services due to under-resourcing or lack of training or knowledge for GPs and RN. How many of these Residents in these RACFs suffer horrific death?

*I believe the goal for QLD government is to alleviate suffering. Freedom is needed for the persons' choice to end their life on their own terms. People need a choice between voluntary assisted dying or GOOD palliative care.*²⁰⁷³

Similarly, General Surgeon Mr Timothy Porter wrote to the committee about the constraints felt by nursing and medical staff to limit the dose of pain relieving medication:

The current model provides for medication to be given as much as possible to relieve pain accepting (under the doctrine of dual effect) that this same medication may hasten the individual's death. Nevertheless, it remains the case that a great proportion of the time the nursing and medical staff feel constrained to limit the dose of pain relieving medication in case

²⁰⁷⁰ Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: Section 7.2.1 in submission 1291, p 75.

²⁰⁷¹ Go Gentle Australia, Submission, 1291, p 75.

²⁰⁷² Submission E1362, p 1.

²⁰⁷³ Submission E087, p 1.

*they might be seen to be trying to hasten death. This has the effect of prolonging the process and the suffering of both the patient and them family.*²⁰⁷⁴

According to Mitchell et al (2019), this fear is unfounded:

*...we have published a systematic review of all Australian case law up until 30 June 2017, including the deliberation of coroners and criminal, civil, performance and conduct proceedings to test the extent to which there have been legal sanctions against health practitioners on the basis of overmedication possibly hastening death, in the setting of life-limiting illnesses. We identified 12 cases in total across all jurisdictions in publicly available electronic databases, and of those, only two had adverse findings recorded. One was dealt with by the Queensland Nursing Council and one by the NSW Civil and Administrative Tribunal. Database searches revealed that neither led to criminal proceedings. This indicates that regulatory bodies are not seeking to blame practitioners when death occurs in the presence of opioid administration, and that the intention to alleviate suffering and adhere to good clinical practice is respected.*²⁰⁷⁵

Committee comment

The committee acknowledges the excellent work of palliative care and other health professionals working to improve the lives of people approaching the ends of their lives. This dedicated group of people help those diagnosed with a life-limiting illnesses to live as well as possible.

The committee appreciates the comments from stakeholders who outlined the many benefits to patients who have access to end-of-life and palliative care services.

Are symptoms adequately managed?

Some health professionals advised the committee that whilst most people who received end-of-life and palliative care had their symptoms adequately managed others did not. There was some difference amongst health professionals as to the size of that cohort.

Some health professionals provided the committee with a description of symptoms other than pain that were complex and difficult to manage. The committee appreciates the frank advice received from the health professionals who gave their time to participate in the inquiry.

Stakeholders other than health professionals told the committee of stories of situations where symptoms were not adequately managed. These harrowing accounts demonstrated that there were many people who suffered severe distress as they neared the end of their life. The committee appreciates the very personal stories that stakeholders shared with the committee. The committee considers that even where end-of-life and palliative care is available, symptom management is not always well controlled and there are a number of people suffering severe distress at end of life.

The committee recognises that many submissions about palliative care were accompanied by a request that the committee recommend that legislating for voluntary assisted dying be introduced in Queensland. The committee will consider voluntary assisted dying in Report No 34.

When symptoms cannot be controlled: the use of palliative sedation

The committee appreciates that in some circumstances symptom control is only achieved through palliative sedation (otherwise known as terminal sedation). Palliative sedation is a normal and compassionate part of responsible patient care at the end of life for the management of intolerable pain and other debilitating symptoms.

²⁰⁷⁴ Submission E1794, p 1.

²⁰⁷⁵ Willmott L, White B, Piper D, et al. Providing palliative care at the end of life: should health professionals fear regulation? *Journal of Law and Medicine* 2018; 26: 214–245 in Geoffrey K Mitchell, Lindy Willmott, Ben P White, Donella Piper, David C Currow and Patsy M Yates, A perfect storm: fear of litigation for end of life care, *Medical Journal of Australia* 2019; 210 (10), p 441.

The committee considers that the intent of palliative sedation is to provide symptom relief for patients, not to hasten their death. The committee notes the legal protections for health professionals where the palliative care was provided in good faith with reasonable care and skill. It acknowledges the guidelines published by Australian and New Zealand Society for Palliative Medicine (ANZSPM) on palliative sedation therapy for palliative medicine specialists.²⁰⁷⁶

The committee notes the concerns of some health professionals that often patients do not choose palliative sedation and there exists a lack of safeguards around this practice.

When symptoms cannot be controlled: patient options

The committee acknowledges the tragic plight of those suffering at the end of their lives, without quality of life, and ‘wanting to go out on their own terms’ who felt the only course of action available to them to end their suffering was to refuse nutrition, hydration or medical treatment.

As evidenced by the experiences shared during the inquiry, the committee notes that dying under these circumstances, can be extremely unpleasant and painful for the victims as well as their loved ones and clinical staff providing care. The committee also notes the unpredictable nature of the dying process in the absence of nutrition and hydration which can lead to a period of distress lasting many days and even weeks.

The committee notes that where a patient has lost capacity, decisions about the withdrawal and withholding of life-sustaining treatment becomes complex and subject to restrictions imposed by the *Powers of Attorney Act 1998*. It considers that a patient’s autonomy is paramount, and a directive made in a valid Advance Health Directive to withdraw or withhold life sustaining treatment including artificial food and hydration should not be subject to legislative restrictions.

The committee recommends that the Government ensure that patients’ directions to withdraw or withhold life-sustaining treatment are followed in accordance with their Advance Health Directive.

Providing effective palliative care: constraints on health professionals

Medical professionals who worked in palliative care advised the committee that the current law in Queensland was complicating the work of health professionals particularly in circumstances where a patient has lost the capacity to make decisions about their health.

The committee appreciates the difficulties experienced by health professionals in applying complex laws in circumstances where the time for the decision making is limited and patients and their loved ones may be experiencing distress.

The committee notes that where a person has impaired capacity, and the treatment involves the withdrawal or withholding of a life-sustaining measure, the doctor requires consent from that person’s substitute decision-maker even if that treatment is futile or non-beneficial. It further notes that, in Queensland, clinicians who seek to withdraw futile treatment without consent commit an offence pursuant to section 79 of the *Guardianship and Administration Act 2000*.

The committee notes that the Queensland Law Reform Commission Report: *A Review of Queensland’s Guardianship Laws*, contains a number of recommendations yet to be implemented which would provide greater clarity for both doctors and patients in Queensland in relation to end-of-life care matters.

Are patients suffering because medical professionals fear legal sanctions?

Inquiry stakeholders reported that patients were suffering because doctors were reluctant to prescribe medication in sufficient doses owing to a fear that they may be prosecuted, sued, sanctioned or blamed for hastening a person’s death. Some stakeholders drew the committee’s attention to letters

²⁰⁷⁶ ANZSPM, 2017, *Guidance Document – Palliative Sedation Therapy*.
<http://www.anzspm.org.au/c/anzspm?a=da&did=1005077>.

posted by the Australian Chief Medical Officer to the GPs who were identified as being within the top 20% of opioid prescribers. Other stakeholders noted that under-treatment in aged care homes and hospitals was common.

The committee notes with concern that the confusion and fear amongst health professionals around lawful treatments for end-of-life and palliative care may result in the denial of adequate symptom relief to patients who go on to experience unnecessary suffering.

The committee recommends that the Queensland Government provides training and information to dispel fears about the law and appropriate medication delivery in palliative and end-of-life care.

Recommendation 76 Further consideration of Queensland Law Reform Commission Report

The committee recommends that the Queensland Government consider the recommendations made by the Queensland Law Reform Commission in their report: *A Review of Queensland's Guardianship Laws* including omission of section 36(2) from the *Powers of Attorney Act 1998* to ensure a patient's directions to withdraw life-sustaining treatment are followed in accordance with their Advance Health Directive.

Recommendation 77 Prescribing of opioids

The committee recommends that the Queensland Government undertake an education campaign for health professionals working in palliative and end-of-life care to ensure understanding of the appropriate use of opioids for palliative and end-of-life care medication.

Appendix A: Aged care facilities operated by Queensland Health

Cooinda House

Dr E A F McDonald Nursing Home

Eventide Charters Towers

Eventide Home Rockhampton

Eventide Nursing Home Sandgate

Forest View Residential Care Facility

Glenbrook Residential Aged Care Facility

Karingal Nursing Home

Milton House

Mt Lofty Nursing Home

North Rockhampton Nursing Centre

Parklands Residential Aged Care Facility

Redland Residential Care Facility

The Oaks Nursing Home

Waroona Multipurpose Centre, and

Westhaven Nursing Home

Source: Queensland Health, correspondence dated 23 January 2019, p 8.

Statement of Reservation

STATEMENT OF RESERVATIONS BY THE LNP MEMBERS OF THE COMMITTEE

Inquiry into Aged Care, End-Of-Life Care and Palliative Care and Voluntary Assisted Dying

AGED CARE

The LNP acknowledges that our Aged Care sector is one of the most important services in our communities as our aging population has people living longer and therefore more and more people each year requiring care.

Queenslanders and indeed all Australians deserve the best quality care in the later stages of life. As the demand for these services increase so too does the pressure on Government budgets to keep up with those demands and maintain quality standards expected.

We acknowledge that the Federal Government made the very welcome and responsible decision to hold an independent and wide-ranging Royal Commission into the aged care sector to ensure that we can continue improve aged care services now and into the future to ensure quality standards are maintained and monitored effectively.

We acknowledge the evidence given by people into significant issues accessing timely and quality care. We acknowledge the horror of some of the evidence given by people of their experiences and thank the people who took the time to share some difficult and emotional stories to the committee.

It is noted by the LNP members of the committee that the report contains 42 recommendations and that 39 of those recommendations call on the Federal Government for various actions. These recommendations need to feed into the wider body of work being undertaken by the Federal Government in the independent Royal Commission.

STATEMENT OF RESERVATIONS

BY THE LNP MEMBERS OF THE COMMITTEE

Inquiry into aged care, end-of-life care and palliative care and voluntary assisted dying

Recommendation 1 *“that the Australian Government allocate funding through the Primary Health Networks in Queensland to trial the use of nurse practitioners in residential aged care facilities. The trial could include expanding their scope of practice to prescribe certain medications and order certain pathology testing for residents in consultation with general practitioners”* fails to explain in practical terms how this could operate. The report does not explore the cross jurisdictional implications of State based funding for nurses or how the federally funded Primary Health Network is able to implement such a trial. The idea itself of having nurse practitioners available has merit but no explanation has been provided of how this could be implemented.

Recommendations 10 to 14 inclusive are recommendations around immediately and completely funding all packages for aged care, removing any wait times and removing caps on places.

Recommendation 10 *“that the Australian Government significantly increase the level of funding it provides to the Home Care Packages Program to ensure packages are sufficient to meet the costs of the required hours of care required for each level package, to clear the current backlog of packages that haven’t been provided.”*;

Recommendation 11 *“that the Australian Government remove its cap on the number of packages available, at all levels, and provides as many packages as are needed. ;*

Recommendation 12 *“that the Australian Government clear the current backlog of packages that haven’t been provided”*;

Recommendation 13 *“that the Australian Government ensure wait times for packages are reduced to a maximum of three months for delivery of all packages across all levels from the date of approval” ; and*

Recommendation 14 that *“Australian Government commit to provide interim care arrangements, close to the approved package level, for applicants for home care packages while waiting for their package to be provided”*

STATEMENT OF RESERVATIONS

BY THE LNP MEMBERS OF THE COMMITTEE

Inquiry into aged care, end-of-life care and palliative care and voluntary assisted dying

These recommendations effectively seek to commence care immediately with no restrictions and commit the Government to immediately and fully fund all requests for aged care without regard to budget implications.

Whilst they are well intended recommendations, we recognise that many will have significant financial impacts. We acknowledge that the Federal Government has responded quickly to the interim report of the Royal Commission announced \$537 million immediate funding for the highest levels of care packages. Federal Government spending increased at an annual average pace of about \$1 billion per year between 2010-11 and 2017-18.

Good government requires prioritisation and recognises the limitations of what can be reasonably offered to ensure equally important and vital areas of government spending are not compromised. In fact, money spent in one portfolio can have a flow on impact to one or more portfolios delivering good outcomes to a sector.

We also wish to express concerns about the lack of detail in the report of from Queensland Health and the facilities they run across Queensland.

In Queensland there were 1088 aged care facilities as at 30 June 2018, with 73 aged care services identified as operated by the State Government in the following service areas:

- Multipurpose Health Services
- Transition Care Program
- Residential Care and
- Home Service Care

The report notes that Qld Health is one of the largest providers of aged care services in the state with 16 residential aged care facilities accounting for around 3% of all aged care beds in Qld, as well as a number of multipurpose facilities and other aged care programs across all parts of the state. One could argue that the committee could have used its extensive inquiry powers to

STATEMENT OF RESERVATIONS

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Inquiry into aged care, end-of-life care and palliative care and voluntary assisted dying

obtain whatever information it wanted from the department about those services, and it would have made an excellent case study for the inquiry to understand the real challenges in aged care.

In a private inquiry briefing (now published) with Queensland Health representatives on 23 January 2019, the Deputy Chair requested on notice that Queensland Health supply our inquiry with the data provided to the Royal Commission which they undertook to provide.

In a Public Briefing—Inquiry into the Health Transparency Bill 2019 MONDAY, 16 SEPTEMBER 2019, Queensland Health confirmed that all of the data they had provided to the Royal Commission had been provided to the parliamentary committee

It is noted that there is very little information about the department's aged care services in the report and nothing about complaints made or audits of the department's facilities. The report is silent on this issue. I think you could call that a missed opportunity.

The Royal Commission continues its important work with their report due in November this year. The LNP members remain confident that the Royal Commission will see recommendations that significantly improve aged care in Australia and in Queensland with the current Federal Government responding quickly and responsibly to their interim report.

The conclusion to the Interim Report commented that *"In due course, we will recommend comprehensive reform and major transformation of the aged care system in Australia. We will chart a new direction for the sector, bringing a clear sense of purpose and of quality, and a renewed focus on compassion and kindness."* The recommendations from our committee need to be considered in light of this impending reform and major transformation and we anticipate that there will be wide ranging recommendations from this important and independent process.

STATEMENT OF RESERVATIONS

BY THE LNP MEMBERS OF THE COMMITTEE

Inquiry into aged care, end-of-life care and palliative care and voluntary assisted dying

PALLIATIVE CARE

This inquiry has revealed alarming and tragic stories of serious deficiencies in Palliative Care in Queensland. The access to good quality palliative care at the end of life should be accessible to all Queenslanders but the inquiry has revealed that we are nowhere near being able to deliver that.

Our inquiry that revealed these serious issues in palliative care also dealt with the matter of Voluntary Assisted Dying (VAD) yet the committee report on the inquiry has been split having a separate report on VAD. The issue of whether or not Queensland should introduce a regime of voluntary assisted dying is inextricably tied to whether or not Queenslanders are able to access quality palliative care at the end of life. The VAD report must be read and considered in conjunction with the concerning revelations of this report from the inquiry.

The LNP members of the committee would like to thank all those members of the community who gave submissions and evidence about very personal and distressing matters often relating to the death of a loved one in harrowing circumstances. We need to do better, and we need to get on with the job. The LNP members of the committee have concerns about how slowly Queensland has moved on this issue having regard to the May 2015 Queensland Health State-wide Strategy for end-of-life care and acknowledge the gaps that still exist despite this as identified in this inquiry. Access continues to be difficult, funding insufficient and workforce development behind where it should be. Deficiencies such as these also identified in the recent Queensland Health Palliative Care Services review in 2019.

Whilst we agree with recommendations around funding increases, we note the minimum amount of funding increases or in some instances decreases in Queensland Health funding for palliative care over the past several years.

An example of this was information provided on notice to the committee by Palliative Care, Queensland Health (requested 10 September 2019) around the percentage of the Gold Coast Hospital and Health Service budget that is for palliative care noting that 2018-19 was 0.67% and 2019-20 is 0.65%.

STATEMENT OF RESERVATIONS

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Inquiry into aged care, end-of-life care and palliative care and voluntary assisted dying

The budget in Queensland seems to hover around the \$100 million mark over the last few years. As noted in the Queensland Palliative Care Services Review 2019:

“Table 3. Activity-based funding for palliative care services (\$,000).

2013-14	2014-15	2015-16	2016-17	2017-18	2018-19
(Actuals)	(Actuals)	(Actuals)	(Actuals)	(Actuals)	(Budget)
\$99,362	\$98,756	\$101,352	\$103,696	\$101,046	\$105,000

Source: Healthcare Purchasing and System Performance Division, Queensland Health, December 2018”

We note that the current year budget is \$105 million for palliative care. We also note an injection of a further \$17 million announcement. We also note how far Queensland is behind other major States in terms of funding for Palliative Care.

Comparing that to the NSW budget spending of around \$210 million per year around double the Queensland budget, which has been boosted further by an extra \$100 million over 4 years on top of that announced in their 2017-18 budget. Victoria has also announced \$72 million increase in palliative care funding and a \$41 million increase in Western Australia over the next 4 years.

We understand the different populations and demographics of the various states but a real commitment needs to be shown. We note that the recommendations made by the committee in the Aged Care section of the report related to federal funding seeks immediate and uncapped assistance for everyone who needs it without regards to budget. These essential services to those at greatest need must be budgeted, properly funded and managed to ensure that we deliver the best possible care to our aged and dying.


Now is the time as a society for governments to recognise the importance and growing need for every persons right to access good quality palliative care. Given the age demographics of the community and the situation pointed out in the Aged Care section of this report demand is going to increase rapidly. We

STATEMENT OF RESERVATIONS

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need to plan carefully with a state wide plan, managed effectively and budgeted sufficiently to ensure this occurs.



Mark McArdle MP
Deputy Chair
Health, Communities, Disability
Services and Domestic and Family
Violence Prevention Committee
Member for Caloundra
Monday, March 23, 2020



Marty Hunt MP
Member
Health, Communities, Disability
Services and Domestic and Family
Violence Prevention Committee
Member for Nicklin
Monday, March 23, 2020

STATEMENT OF RESERVATIONS

BY THE LNP MEMBERS OF THE COMMITTEE

Inquiry into aged care, end-of-life care and palliative care and voluntary assisted dying

