

**Palliative and community care
in Queensland:
toward person-centred care**

Report No. 22

Health and Community Services Committee

May 2013

Health and Community Services Committee

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Abbreviations

ABF	Activity Based Funding
ABS	Australian Bureau of Statistics
ACP	acute care planning
AHD	Advance Health Directive
AIHW	Australian Institute of Health and Welfare
AMAQ	Australian Medical Association Queensland
ANZSPM	Australian and New Zealand Society of Palliative Medicine
ARP	Acute Resuscitation Plan (p81)
CALD	culturally and linguistically diverse
Carer Recognition Act	<i>Carer Recognition Act 2010 (Cwlth)</i>
Carers Act	<i>Queensland Carers (Recognition) Act 2008</i>
cdmNet	chronic disease management system
COAG	Council of Australian Governments
the committee	Health and Community Services Committee
COTA	Council of the Ageing Queensland
CPR	cardio-pulmonary resuscitation
CSCF	Clinical Services Capability Framework
Cwlth	Commonwealth
Department of CCSDS	Department of Communities, Child Safety and Disability Services
DOHA	Department of Health and Ageing (Cwlth)
EoL	end of life
EPOA	enduring power of attorney
GP	general practitioner
HACC	Home and Community Care
HHS	Hospital and Health Service
HHWR (NPA)	Health and Hospital Workforce Reform (NPA)
HITH	Hospital in the Home
ieMR	integrated electronic medical record
IHPA	Independent Hospital Pricing Authority
IPHS (NPA)	Improving Public Hospital Services
MASS	Medical Aids Subsidy Scheme
MBS	Medicare Benefits Schedule
MJA	Medical Journal of Australia
MSPCS	Metro South Palliative Care Service
NBN	national broadband network
NDA	National Disability Agreement
NDIS	National Disability Insurance Scheme
NGO	Non-Government Organisation
NHHN	National Health and Hospitals Network
NHMRC	National Health and Medical Research Council
NPA	National Partnership Agreement
NRCP	National Respite for Carers Program

NSAP	National Standards Assessment Program
PCA	Palliative Care Australia
PCC4U	Palliative Care Curriculum for Undergraduates
PCCIMS	(Palliative Care) Clinical Information Management System
PCEHR	personally controlled electronic health record
PCOC	Palliative Care Outcomes Collaboration
PCQ	Palliative Care Queensland
PEPA	Program of Experience in a Palliative Approach
POA	power of attorney
PPCS	Paediatric Palliative Care Service
PTSS	Patient Transport Subsidy Scheme
QAS	Queensland Ambulance Service
QPS	Queensland Police Service
RAC EoL	residential aged care end-of-life care pathway
RACF	residential aged care facility (nursing home or hostel)
RACGP	The Royal Australian College of General Practitioners
RACP	Royal Australasian College of Physicians
Senate Committee inquiry	Senate Community Affairs References Committee, <i>Palliative care in Australia, 2012</i>
UK	United Kingdom
WHO	World Health Organization

Queensland Hospital and Health Services

Cairns and Hinterland Hospital and Health Service
Cape York Hospital and Health Service
Central Queensland Hospital and Health Service
Central West Hospital and Health Service
Children's Health Queensland Hospital and Health Service
Darling Downs Hospital and Health Service
Gold Coast Hospital and Health Service
Mackay Hospital and Health Service
Metro North Hospital and Health Service
Metro South Hospital and Health Service
North West Hospital and Health Service
South West Hospital and Health Service
Sunshine Coast Hospital and Health Service
Torres Strait and Northern Peninsula Hospital and Health Service
Townsville Hospital and Health Service
West Moreton Hospital and Health Service
Wide Bay Hospital and Health Service

Source: Queensland Health, *Queensland public hospitals and health care facilities*, accessed 10 May 2013 from: <http://www.health.qld.gov.au/services/default.asp>

Glossary

Important terms that are critical to the inquiry are defined or described below.

activity based funding	The system of national classifications, cost weights and nationally efficient prices used to fund public hospital services provided to individual patients in Australia.
admitted patient	A person who undergoes a hospital's formal admission process as either a same-day patient or an overnight stay patient to receive treatment and/or care. Treatment or care may be provided in hospital or in the person's home (through a Hospital in the Home service). See also <i>non-admitted patient</i>
advance care planning	A process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known so they can guide decision-making at a future time when that person cannot make or communicate his or her decisions. ¹
advance health directive	In Queensland, a document in which an adult may give directions about their future health care preferences, and may appoint an attorney/s to make decisions on their behalf if the directions are inadequate. Under the <i>Powers of Attorney Act 1998</i> an advance health directive comes into effect only after the person who made it has impaired capacity and is not able to make or communicate their own decisions. <i>Note: in other Australian jurisdictions the term "advance care directive" refers either to a common law document about future health preferences, to legislated instruments to record directions, or as a collective term for documents containing health directives, appointment of an enduring guardian and common law directives.</i> ²
allied health profession	Health professions which include occupational therapy, pharmacy, physiotherapy, psychology, social work and speech pathology.
ambient living	The incorporation of assisted technology solutions into a person's environment and is commonly considered in settings which cater for the elderly or people with a disability. ³
ambulatory care / setting	Health care services provided on an outpatient basis, including diagnosis, treatment and rehabilitation.
bed equivalent	Under the National Partnership Agreement on Improving Public Hospital Services, targets for the growth of sub-acute services (which currently includes palliative care) are measured in 'beds' or 'bed equivalents'. A bed equivalent refers to an occasion of service delivered in the community/home rather than in a hospital bed.

¹ Australian Health Ministers' Advisory Council (AHMAC), *A National Framework for Advance Care Directives*, 2011, Clinical, Technical and Ethical Principal Committee, p.9, available at http://www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.pdf

² AHMAC, *ibid.*, p.9

³ James Barrientos, Chief Executive Officer, LifeTec, *Public Hearing Transcript*, 24 August 2012, p.9

care worker	A paid worker who provides care services, e.g. housework or personal care services in a client's home or in a residential aged care facility. Care worker roles are diverse; care workers may be unqualified or have a Certificate III or IV, or for some roles, a diploma qualification.
carer	Someone, who through family relationship or friendship, looks after a frail older person or someone with a disability or a chronic or terminal illness. In this report the term is used exclusively to describe the providers of unpaid or 'informal' care.
community care services	Community care services include nursing care; allied health care such as physiotherapy and occupational therapy; meals and other food services; domestic assistance; personal care; home modification and maintenance; transport; Centre-based day care; respite care; counselling, social support, information and advocacy; and case management and assessment.
consultation / liaison service	Consultation and advice service provided by a specialist palliative care service for other health and care providers (specialist and primary care; public and private sector) to support non-palliative care specialists to care for patients using a palliative approach.
end of life care	The phase of palliative care that occurs closer to the end of life. Some clinicians consider palliative care during the last weeks or days of life to be end of life care; others consider that the period of the last three, six or 12 months of life to be approximate time for end of life care.
episode of care	A phase of treatment; there may be more than one episode of care during a patient's stay in hospital.
general practice	Person-centred, continuing, comprehensive and coordinated whole person health care to individuals and families in their communities. ⁴
hospice	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. Some hospices also provide specialist palliative care in a person's home.
Hospital in the Home (HITH)	Care provided to admitted patients in their place of residence as a substitute for hospital accommodation, e.g. care may be provided in a residential aged care facility or a person's own home. HITH is an example of hospital substitution or hospital avoidance.
Hospital and Health Service (HHS)	Hospital and Health Services are statutory bodies and are the principal providers of public sector health services in Queensland including public hospital services and a range of primary and community services. Each Hospital and Health Service is accountable to a local Hospital and Health Board.
hospital separation	The process by which an episode of care for an admitted patient ceases.
hospital substitution and avoidance	Alternative models of care that aim to reduce the need for patients to either be admitted to, or remain in hospital, e.g. Hospital in the Home or hospital in the nursing home.

⁴ The Royal Australian College of General Practitioners (RACGP), *What is general practice?*, accessed 23 April 2013 from <http://www.racgp.org.au/becomingagp/what-is-a-gp/what-is-general-practice/>

in place	Used to describe the place of a person's care, e.g. 'ageing in place', or 'die in place' may refer to a person remaining in their own home, in a residential aged care facility, or other place where the person lives.
in-reach service	A service provided by a health service visiting a residential aged care facility (nursing home) to reduce the need for transfer of aged care residents to an emergency department or acute hospital care if appropriate and safe care can be provided in their own environment.
life-limiting condition or illness	A condition or illness where it is expected that death will be a direct consequence of the specified condition or illness. Palliative Care Australia advises in its glossary of terms that the use of 'terminal condition' is preferred to 'life-limiting condition'. When discussing paediatric palliative care, however, life-limiting condition is the more commonly used term and it is used in this report in that context. See also <i>terminal condition</i>
medical deputising service	An organisation which directly arranges for doctors to provide after-hours medical services (home visits, and possibly telephone triage/medical advice services) to patients of other practices, usually between 6.00pm and 8.00am. ⁵
non-admitted patient	A patient who does not undergo a hospital's formal admission process. Non-admitted patients include emergency department patients, outpatients, other patients who are treated by hospital staff but not in hospital, e.g. community outreach.
occasion of service	A consultation, examination, treatment or other service provided to a non-admitted patient, e.g. an outpatient consultation.

⁵ Based on: National Association for Medical Deputising Australia Limited, *Definition of a Medical Deputising Service*, accessed 23 April 2013 from <http://www.namds.com/pdf/NAMDS%20MDS%20defn%20April08.pdf>

<p>palliative care</p>	<p>The World Health Organization (WHO) definition recognises that palliative care may be provided by non-specialists; this definition is also used in the <i>National Palliative Care Strategy</i>.⁶</p> <p>Palliative care is defined by the World Health Organization as:</p> <p><i>... an approach that improves the quality of life of patients and their families facing the problems 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.</i></p> <p><i>Palliative care:</i></p> <ul style="list-style-type: none"> • <i>provides relief from pain and other distressing symptoms</i> • <i>affirms life and regards dying as a normal process</i> • <i>intends neither to hasten or postpone death</i> • <i>integrates the psychological and spiritual aspects of patient care</i> • <i>offers a support system to help patients live as actively as possible until death</i> • <i>offers a support system to help the family cope during the patients illness and in their own bereavement</i> • <i>uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated</i> • <i>will enhance quality of life, and may also positively influence the course of illness</i> • <i>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 complication.</i> <p>In addition, the WHO states that palliative care for children:</p> <p><i>is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress.</i></p> <p><i>Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes.</i>⁷</p>
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⁶ Department of Health and Ageing (DOHA), *National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End of Life*, 2010, Canberra, p.4, available at [http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/\\$File/NationalPalliativeCareStrategy.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/$File/NationalPalliativeCareStrategy.pdf)

⁷ World Health Organization (WHO), *WHO Definition of Palliative Care*, accessed 8 January 2013 from <http://www.who.int/cancer/palliative/definition/en/>

palliative approach	An approach to health care that aims to improve the quality of life of individuals with a terminal illness, and includes symptom management, active comfort care and addressing physical, cultural, psychological, social and spiritual needs. It is underpinned by an open attitude to death and dying. ⁸
palliative medicine	The specialist branch of medicine with training and expertise in palliative care. Palliative medicine specialists have successfully completed advanced training with Royal Australasian College of Physicians.
primary health care <i>and</i> primary health care provider	Health providers such as general practitioners, nurses, Aboriginal Health Workers and others who provide the primary or first level of health care to individuals, families and communities. The WHO defines primary health care as: <i>Essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process.</i>
residential aged care facility	Accommodation and care facilities for aged residents; commonly known as nursing homes and aged care hostels.
Senate Committee Inquiry	Senate Community Affairs References Committee inquiry into palliative care. Its report, <i>Palliative care in Australia</i> , was tabled in the Senate in October 2012.
separation	See <i>hospital separation</i>
subacute care	The care and treatment that is between acute care and chronic care, for example rehabilitation, for a condition of moderate duration and seriousness. In Commonwealth-State funding arrangements, palliative care is currently categorised as part of subacute care.
terminal condition	A progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant illness and ageing. Palliative Care Australia advises in its glossary of terms that the use of 'terminal condition' is preferred to 'life-limiting condition'. See also <i>life-limiting condition or illness</i>

⁸ Adapted from: National Health and Medical Research Council (NHMRC), *Guidelines for a Palliative Approach in Residential Aged Care*, Enhanced version – May 2006, Canberra, pp.3–4, available at http://www.nhmrc.gov.au/files_nhmrc/publications/attachments/pc29.pdf

Terms of reference

On 7 June 2012, the Legislative Assembly resolved:

1. That the Health and Community Services Committee inquire into and report on Queensland's chronic, frail and palliative care services.
2. That in undertaking this inquiry the committee should consider:
 - the capacity and future needs of these services (including children and adolescents palliative care)
 - the effectiveness, efficiency and adequacy of palliative, frail and chronic care services
 - examine opportunities for reforms to improve collaboration and cooperation between chronic, disability and other health services, and
 - consideration of segmenting the current Home and Community Service system based on age of the client, needs of the client, their carer and the providers.
3. Further, that the committee take public submissions and consult with key industry groups, carers, health workers and relevant experts.
4. The committee is to report to the Legislative Assembly by 28 February 2013.

The reporting date was subsequently extended to 28 May 2013.

Chair's foreword

I think a way that a society or community is able to determine its health is to look at how it treats or deals with its most vulnerable.

An inquiry into palliative care leads to an understanding that there is conversation our community needs to have, even if it is sometimes difficult. We need to talk about dying. If we can talk about dying, at a community and individual level, and with our health providers, we will be better able to enhance the quality of life for people with a terminal illness.

People who need palliative care or home care – and their carers - need the community as a whole to have a robust and respectful debate about community expectations of the standard of care we feel is acceptable at the end of life, and in home care. This report tackles some very difficult issues and aims to make recommendations that will lead to better outcomes for people who need palliative care and community care.

The committee recognises that it is not possible to expand and improve all palliative care and community care services at once. As a community we need to consider and talk about priorities in how we care for people who are vulnerable, and people who are dying. While the committee's report recommends actions by government, and will no doubt be considered by the Ministers and Cabinet, I hope that as Queenslanders we will engage in discussions about how we think palliative care and community care should be delivered. A community conversation can inform the decisions that government makes on these complex and important issues.

I hope that this report sparks debate across Australia about these important issues. I believe this is one of the most comprehensive inquiries held by any parliament in Australia into palliative care and its crossover into community care.

On behalf of the committee, I thank all of the people and organisations who made submissions, appeared as witnesses, participated in the committee's roundtable discussions, or assisted in other ways. Some people wrote submissions about their personal experiences, and we are especially grateful for their generous contributions to a community conversation about dying and palliative care.

I thank all committee members, current and past, who contributed to this report for their earnest efforts to deliver a quality report to the Queensland community. Thanks also to the committee's secretariat for their outstanding effort in the preparation of this report. I also want to thank the Hansard staff for assisting the committee with its work.

I believe this report will be a reference point for conversation and debate well into the future as the community considers palliative care and community care. I trust it will lead to better outcomes for those with terminal conditions, and those who need home care.



Trevor Ruthenberg MP

Chair

Executive summary

1. Introduction and policy context

The Health and Community Services Committee (the committee) was asked by the Legislative Assembly in June 2012 to inquire into and report on palliative care services and chronic and frail services. The terms of reference encompass the portfolio responsibilities of the Minister for Health and the Minister for Communities, Child Safety and Disability Services.

It did this against the background of national health reforms and establishment in Queensland of Hospital and Health Services as statutory bodies. The Commonwealth's aged care reforms (*Living Longer, Living Better*), development of the National Disability Insurance Scheme and Queensland reforms to enable self-directed funding for people with a disability were part of the background to the committee's work. In addition, the committee was asked to consider the segmentation of the Home and Community Care program, which occurred in July 2012. The matters the committee inquired into meant that policies about support for carers were also an important consideration.

2. Current palliative care and community care services in Queensland

Palliative care

Specialist palliative care is provided in the public and private health sectors and by non-government organisations. Public sector specialist palliative care services range from nursing and allied health care during business hours (Clinical Services Capability Framework (CSCF) Level 1), to multidisciplinary inpatient and home care services with the capacity to manage patients with the most complex symptoms (CSCF Level 6). The most specialised services (CSCF Levels 5 and 6) are located in the south-east of Queensland and in Townsville. A state-wide paediatric palliative care service is provided by Queensland Children's Hospital and Health Service.

Much of the care provided to people with a terminal condition is delivered by general practitioners, other primary healthcare professionals, and by medical and nursing specialists in fields other than palliative care, particularly oncology. A growing proportion of people with terminal conditions live in residential aged care facilities (RACF).

Queensland has a small number of hospices, all operated by non-government organisations. Some provide both inpatient and home care, and others provide only home-based care. A business hours palliative care telephone information and support service is operated by Karuna Hospice.

Community care

The committee received limited evidence about community care services and disability services. Queensland Community Care Services are provided, mainly through non-government organisations, for people with a moderate to profound disability or condition which restricts their ability to carry out activities of daily living. Clients may be charged a fee for services based on their capacity to pay. Just over half of the consumers of Queensland Community Care Services in 2010–11 received services for less than one hour a month.⁹

3. Palliative care in Queensland – future directions

Capacity of services and needs

Palliative care aims to improve the quality of life for a person with a terminal illness by preventing and relieving pain and other distressing symptoms, and integrating psychological and spiritual care. Palliative care regards dying as a normal process and intends neither to hasten nor postpone death.

⁹ Department of Communities, Child Safety and Disability Services (DCCSDS), Submission no.76, p.8

Evidence to the committee indicated that palliative care is “... extremely well done in some areas, but not available in others.”¹⁰ The committee was told that referrals and the average number of patients have increased significantly in recent years, and that the need is already unmet and increasing.¹¹ In response to increased need, some specialist palliative care services have reduced the range of services they provide. For example, the Mater Palliative and Supportive Care Service no longer provides a home-visiting service.¹² Others have tightened their eligibility criteria, and no longer provide access to non-cancer patients, or to residents of RACFs, or those with a prognosis of more than three months.¹³ The existing capacity of palliative care services is stretched, and services are not able to meet current needs.

Effectiveness and efficiency of palliative care services

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
- 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.

One element of the palliative care system that the committee recognised as important is the establishment of a 24-hour state-wide palliative care telephone information, referral and support service, staffed by skilled nursing and allied health staff and supported by an internet information service (Recommendation 1).

The committee notes the importance of palliative care standards and benchmarking of service quality to achieve high quality services. While Queensland’s palliative care services have a high rate of participation in the Palliative Care Outcomes Collaboration, the committee recommends that further effort be made to encourage all palliative care services to participate (Recommendation 2).

Future needs for palliative care

Australia’s ageing and growing population, along with increases in both the incidence of chronic disease and people living longer with chronic conditions, will increase the need for palliative care. As people with chronic disease become an increasing proportion of those who need palliative care compared to cancer patients, services will need to respond to variable disease and palliative care trajectories. Some patients may need palliative care services intermittently over a longer period of time to manage complex pain, while others may need both treatment and palliative care at the same time.

¹⁰ Palliative Care Australia (PCA), Submission no. 69, p.3

¹¹ Palliative Care Queensland (PCQ), Submission no. 74, pp.6 & 9; Professor Rohan Vora, on behalf of the Senior Leadership Clinical Team Gold Coast Health and Hospital Service, Submission no. 73, p.4; The Karuna Hospice Service Ltd., Submission no.13, p.6

¹² Professor Janet Hardy and Decima Jones, Submission no. 16, p.4

¹³ PCQ, *ibid.*, p.9

Residential aged care facilities

The need for more focus on palliative care in RACFs has been recognised nationally and in evidence to the committee. Unmet need for palliative care in RACFs can result in unnecessary transfers to acute hospital care and reducing those transfers would improve end-of-life outcomes for older patients and assist in constraining acute care costs.¹⁴ The committee noted some important Queensland led initiatives, including a Palliative Approach Toolkit for RACFs.¹⁵

Children and adolescents

The expected death of a child or adolescent is felt particularly intensely and the needs of young people and their families differ from those of adults. Among other things, palliative care for children and adolescents needs to take account of the child's developmental stage and the bereavement support needed. The committee heard that it was difficult to access information about the available palliative care services, and that parents did not always receive timely information about palliative care.¹⁶

Submissions and evidence said there is inadequate access to bereavement and counselling services.¹⁷ The lack of a paediatric hospice was highlighted by 15 submissions.¹⁸ The committee considers that there is a clear need for hospice care for children and adolescents and their families (Recommendation 3).

Aboriginal and Torres Strait Islander people's needs

Aboriginal and Torres Strait Islander people have higher rates of chronic disease than others, and shorter life expectancy. Generally, Aboriginal and Torres Strait Islander people have a relatively high level of need for palliative care at a younger age. Coupled with cultural requirements and remoteness, this places unique demands on palliative care service provision.

Evidence to the committee emphasised the importance of culturally appropriate care, and challenges arising from relocation to a regional city for treatment or care. The committee recommends targeted training for palliative care staff in cultural issues, measures to ensure that palliative care services and Aboriginal and Islander Health Services are aware of the Patient Travel Subsidy Scheme and consideration of accommodation for patients, family and friends when patients are away from home for palliative care and related treatment (Recommendations 4 to 6).

Access to palliative care services – rural and regional needs

The committee heard that access to palliative care services in rural and remote areas is not equitable, and was informed of some of the challenges in delivering accessible services. People who wish to die at home may be discouraged by the distance to assistance if they have uncontrolled pain or other symptoms.¹⁹

Travel to major centres for treatment adds to burdens for people from rural and remote areas. The committee has made recommendations that it anticipates would contribute to improved access for

¹⁴ Dr Mark Deuble, Member, Australian Medical Association Queensland (AMAQ), *Public Hearing Transcript*, 24 August 2012, p.29

¹⁵ The University of Queensland / Blue Care Research and Practice Development Centre, *Palliative Approach Tool Kit*, accessed 7 January 2013 from <http://www.ug.edu.au/bluecare/the-palliative-approach-toolkit>

¹⁶ Name suppressed, Submission no. 33, p.5; CanTeen, Submission no. 36, p.3

¹⁷ Wesley Mission Brisbane, Submission no. 26; Brett and Louise Carter, Submission no. 30; Queensland Kids, Submission no. 32; CanTeen, *ibid.*; Name suppressed, Submission no. 42; and PCQ, Submission no. 74

¹⁸ Jennie Martin, Submission no. 3; Brett and Louise Carter, *ibid.*; Queensland Kids, *ibid.*; Name suppressed, Submission no. 33; CanTeen, *ibid.*; Regina Miller, Submission no.41; Name suppressed, Submission no. 42; St Vincent's Hospital Brisbane, Submission no. 44; Nicole Lipp, Submission no. 53; National Disability Services, Submission no. 54; Tiffany and Malcolm Heddes, Submission no.56; Queensland Nurses Union, Submission no. 66; Fiona Engwirda, Submission no. 70; Anglicare Southern Queensland, Submission no. 72; and PCQ, Submission no. 74

¹⁹ Kincare, Submission no. 39, p.5

rural and remote residents. Those recommendations relate to specialist palliative care services, consultancy liaison services for GPs and other health providers, training, use of videoconferencing and support for carers.

Future palliative care services – palliative care in the community

Many people can receive adequate palliative care at home from primary health care providers, supported by specialist services as required. General practitioners, nurse practitioners, nurses and allied health professionals are important providers of palliative care. Patients and families are often supported by non-government service providers, volunteers and unpaid carers. In RACFs, enrolled nurses and personal care workers are also important members of the palliative care team.

The committee understands that most people with a terminal condition prefer to receive care at home for as long as possible, and that not everyone needs specialist palliative care services. The importance of providing care in the setting of choice, combined with the high cost of inpatient hospital care, makes it important for Queensland to increase its capacity to deliver a palliative approach in the community, including in RACFs.

Support from specialist palliative care services

Specialist palliative care services have an important role in supporting GPs and other health providers, however that support is not consistently available. The committee considers that the provision of consultation and shared care services by specialist palliative care services is essential to facilitating quality palliative care in the community. It is expected that additional resources will be required to ensure that specialist services can provide the required level of consultancy. An investment in specialist services to provide consultation services and support home-based care would be offset by a reduction in acute hospital costs from unnecessary and unwanted hospital admissions.

Representatives of GPs argued that palliative care work is not sufficiently remunerated. The committee has recommended that this be raised with the Commonwealth (Recommendation 10).

Residential aged care facilities

There is an increasing level of need for palliative care in RACFs, and less GPs who offer home visits and palliative care. The committee was told that “RACFs are the hospices of today and likely to remain so in the future. Nonetheless there is professional consensus that people in RACFs frequently receives less than quality palliative care.”²⁰ A successful Queensland initiative to implement of an end-of-life pathway in RACFs has reduced acute hospital admissions from RACFs. The end-of-life pathway was accompanied by training for RACF staff, telephone support for GPs and RACF staff, and a medication imprint system. It resulted in significantly less transfers from RACFs to acute hospitals and enabled more residents of RACFs to die ‘in place’ rather than in hospital.²¹

Factors affecting viability of care at home

The committee received evidence about factors that affect the viability of palliative care at home. A significant factor in whether patients can receive care at home is the capacity of unpaid carers to provide the level of direct care that the person needs, and to have access to the information and guidance they need.

Timely access to affordable specialist equipment is often required for home palliative care. Submissions described difficulties in accessing equipment quickly. While some palliative care services provide an affordable equipment loan service, evidence suggested this was uncommon. The

²⁰ Professor Liz Reymond, Submission no. 11, p.4

²¹ Reymond L, Israel F and Charles M, ‘A residential aged care end-of-life care pathway (RAC EoLCP) for Australian aged care facilities’, *Australian Health Review*, 2011, Vol.35, p.351

committee's recommendation is that all public sector palliative care services should operate or facilitate timely access to a palliative care equipment loan service (Recommendation 14).

The committee noted that Hospital in The Home (HITH) initiatives have the potential to deliver high levels of patient and carer satisfaction. It believes that Queensland Health should encourage the use of palliative care HITH as a substitute for acute inpatient care.

Palliative Care Queensland told the committee that "stressed family members call the ambulance service or police service when someone dies, rather than the palliative care service."²² Other submissions and witnesses elaborated on the sometimes unwanted sequence of events that may follow, particularly if a person dies after hours and a doctor is not available to certify death.

The committee notes that the role of ambulance staff is primarily to provide life-saving treatment, and there is a tension between this role and the response that is required in a palliative care situation. The committee also noted that evidence to the Senate Committee inquiry demonstrated that, with appropriate documentation and protocols in place, a more person-centred approach is possible.²³ The committee has recommended that protocols be developed for an expected death at home or in a RACF (Recommendation 15).

Hospices

Queensland has a small number of hospices run by non-government organisations which rely significantly on fundraising for their operational costs. While most people would prefer to stay at home for as long as possible, the reality for some people is that worsening symptoms mean that dying at home is not possible. In those circumstances, a hospice with inpatient beds may be the next preference. The committee has recommended that resources be sought for additional hospice beds and/or new hospices (Recommendations 16).

Future palliative care services – specialist services

A consistent theme in evidence presented to the committee was the desirability of providing palliative care for as long as possible at home or in a RACF, and reducing the frequency of unwanted and unnecessary admission to hospital via emergency departments. Specialist palliative care services with adequate service capacity are a key component of a system that can provide person-centred care at home.

The committee recognises that public sector specialist palliative care services vary in the level of services they provide according to the Clinical Services Capability Framework (CSCF) and recognises the important role of HHS in local planning. The committee endorses the view of submitters and witnesses that higher CSCF level specialist services should provide, in addition to direct care for patients with complex palliative care needs, a broad range of services, particularly:

- consultation service to support other health providers
- visiting or in-reach services to RACFs
- 24 hour on-call services for patients at home, potentially in collaboration with GPs and nurse practitioners
- training and support for home carers, and volunteer coordinators to train and support volunteers to provide in-home respite and carer support
- specialist bereavement counselling
- equipment loan services, and
- continuing education and capacity building for health professionals in palliative approaches.

²² PCQ, Submission no. 74, p.51

²³ Amaranth Foundation, evidence to Senate Community Affairs References Committee (Senate Committee inquiry), *Palliative care in Australia*, 2012, Canberra, p.66

Specialist palliative care services with those roles may not directly deliver all of those services. They would however have responsibility for ensuring that other health and care providers have the capacity to provide palliative care according to people's needs. This might mean contracting specialist bereavement counselling from another organisation, or sharing an equipment loan service with a neighbouring HHS. The committee has recommended work toward resourcing higher level specialist palliative care services to provide this range of services (Recommendation 17).

Several stakeholders recognised the importance of formalising links between specialist palliative care services which have capacity to provide consultancy advice, with generalist services. Given the current distribution of higher level specialist palliative care services, those linkages or partnerships between specialist and non-specialist services, including GPs, will cross HHS boundaries. The committee has recommended that the most effective framework for linkages be planned (Recommendation 18).

Workforce capacity

A key requirement to deliver person-centred palliative care according to need is to ensure sufficient workforce capacity. In addition to improving the capacity of health providers to deliver care using a palliative approach, and to increase the number of specialist palliative care physicians and nurse practitioners, continued effort is needed to replace retiring health providers.

The committee considers that more palliative medicine specialists are needed in Queensland. The committee was told that Australia has only 0.5 full-time equivalent palliative medicine specialists per 100,000 of population, and that the acceptable benchmark is between one and 1.5 specialists per 100,000.²⁴ The committee has recommended that specialist palliative care services should have the capacity to train palliative medicine specialists. The committee also heard that nurse practitioners have a significant potential role in palliative care, and has recommended scholarships to encourage nurses to complete the necessary training, along with efforts to encourage nurse practitioners into palliative care (Recommendations 19 and 20).

Enhancing the capacity of non-palliative care health professionals in a palliative approach is essential, and the committee has recommended steps to embed this education and training (Recommendations 21 to 25).

Telehealth and eHealth

Recent and new technologies have considerable potential to improve the quality and delivery of palliative care. In a geographically dispersed state, full use of modern technology may overcome some of the challenges of distance. Queensland has an extensive network of more than 650 telehealth (videoconference) sites. The committee considers there is potential to improve palliative care services by increased use of telehealth for patient consultations, advice to health providers and for training. The committee has recommended that greater use of videoconferencing be promoted and that the development of national telehealth and eHealth initiatives that are suitable for use across public, private and community settings continue to be supported (Recommendations 26 and 27).

Public awareness and education

The need to improve awareness and understanding of palliative care and of death as part of life is well recognised in the palliative care community and by governments. The committee believes that a community conversation about the normality of dying is important. Greater awareness and open discussion can enable people to make choices about where and how they want to be treated as they approach the end of life. In the committee's view, improving public education is necessary to encourage advance care planning and increase the use of Advance Health Directives.

²⁴ Australian and New Zealand Society of Palliative Medicine (ANZSPM), Submission no. 51, p.6 & 7; The Royal Australasian College of Physicians (RACP), Submission no. 25, p.6;

The *National Palliative Care Strategy* recognises the importance of improving understanding, and sets out actions which include development of a “comprehensive, evidence based, multi-modal and targeted national public awareness strategy to promote death as a normal part of living and promote available series and options”.²⁵ The committee has recommended promotion of early implementation of a national public awareness campaign (Recommendation 28). The committee noted evidence that some health providers do not discuss palliative care or make timely referrals, and notes that access to professional development in a palliative approach may assist in open communication about a patient’s prognosis and palliative care.

Advance care planning and Advance Health Directives

Advance care planning is possible only if patients, families and health providers are able to discuss emotionally difficult issues. The committee considers that a public awareness campaign that normalises death and dying as part of life would facilitate more advance care planning. Planning ahead for our own end of life is more likely to result in our wishes being respected and implemented. Advance care planning has been shown to improve end of life care, improve patient and family satisfaction and reduce stress, anxiety and depression in surviving relatives.²⁶ The committee recommends that the Senate Committee recommendation for a national awareness campaign and funding for advance care planning be supported (Recommendations 29).

Palliative Care Australia has argued for a single common legislative requirement for Advance Health Directives.²⁷ A number of submitters and witnesses supported nationally consistent legislation about advance health decisions.²⁸ The committee notes that complex legal, ethical and clinical issues underpin discussion of Advance Health Directives and the extent to which they are followed. The committee acknowledges that there are unresolved issues in Queensland’s legislative system of AHDs and that there are diverse views on some of those issues. The committee has recommended that consideration be given to referring to it an inquiry into the law that applies to AHDs (Recommendation 30).

Resourcing and delivering needs-based and person-centred palliative care

Funding arrangements for palliative care have changed as national health reforms are implemented. Submitters recognised the funding contribution of both the Queensland and Australian governments, and evidence presented to the committee supported the view that palliative care in Queensland is currently under resourced. The development of services was described as ‘erratic’ and ‘ad hoc’, and inequities in the system have developed over time.²⁹

Work is needed to progressively improve the capacity to provide high quality palliative care. The committee considers that a state-wide palliative care strategy is needed to guide work to increase the capacity of the service system to meet current and future needs. A state-wide strategy could set guide the provision, planning, funding and delivery of palliative care services, and provide clear aims and guidance to public, private and non-government providers of palliative care. To facilitate planning, the committee has recommended early development of a state-wide palliative care strategy (Recommendations 32 and 33), mapping of existing services including external review of self-assessed CSCF levels of palliative care services (Recommendations 34), a state-wide population

²⁵ DOHA, *National Palliative Care Strategy 2010*

²⁶ Detering KM, Hancock A, Reade MC, Silvester W, ‘The impact of advance care planning on end of life care in elderly patients: randomised controlled trial’, *British Medical Journal*, April 2010, Vol.340, No.7751, c1345, p.847

²⁷ PCA, *Advance Care Planning*, accessed 26 April 2013 from <http://www.palliativecare.org.au/Portals/46/PCA%20Advance%20Care%20Planning%20Position%20Statement.pdf>

²⁸ Blue Care and UnitingCare Health, Submission no. 24, p.19; PCQ, Submission no. 74, p.49; Australian Medical Association Queensland (AMAQ), Submission no. 67, p.5

²⁹ PCQ, Submission no. 74, p.12; Professors Patsy Yates and Ross Young, Submission no. 65, p.1; Professor Rohan Vora, PCQ, *Public Hearing Transcript*, 22 August 2012, p.7

based assessment of Queensland's palliative care needs (Recommendations 35) and review of Queensland Health's planning benchmarks (Recommendations 36).

Submissions to the committee noted a lack of clarity and transparency about funding arrangements, including the 'bundling' of national palliative care funding into 'subacute' funding, and concerns that the implementation of Activity Based Funding as part of national health reforms may not take account of important aspects of palliative care such as consultation services with other health providers. The committee has recommended annual reporting by Queensland Health of palliative care service provision and expenditure, and support of the Senate Committee inquiry Recommendations about subacute funding and costing of palliative care services by the Independent Hospital Pricing Authority (Recommendations 37 to 39).

Health reform creates opportunities for new and more planned approaches to the funding and provision of palliative care, to better meet needs. The committee has recommended a broad role for specialist palliative care services, including consultation services to support other health providers, training, specialist bereavement services and equipment loan. The committee considers that the funding available to existing specialist palliative care services and the potential for funding of additional services in other regional areas, based on a population needs assessment, should be investigated as soon as possible.

As system manager, Queensland Health has an important role in planning for and supporting the progressive implementation of accessible palliative care across the state, using service agreements and purchasing arrangements to facilitate this. The committee has recommended that the Minister for Health ensure that the system manager ensure that HHS deliver more services in the home and community, implement the CSCF, make links between specialist palliative care services and other health services to provide consultation services, ensure case management and discharge planning are undertaken, and deliver comprehensive palliative care services (Recommendations 40). The committee has also recommended evaluation of innovative models of palliative care, the provision of information and guidance to HHS about best practice and a program of research about models of palliative care (Recommendations 41).

Community care and home care services – capacity, needs and future directions

The committee's terms of reference required it to consider the capacity, needs, effectiveness and efficiency of Queensland's Community Care Services. As noted above, very limited evidence was received.

Submitters were concerned about inadequate information about services and eligibility. The committee considers that currently available information about access to Queensland Community Care Services is inadequate and notes that a trial of Community Access Points is due for completion in June 2013. The committee sees the benefit of a seamless link between a single phone number and a regional information, assessment and referral service which has the benefit of local knowledge. The committee also considers that case management is needed for people who need services from more than one provider, and that a regional information and assessment service could fulfil this role. The committee has recommended implementation of an information, referral, assessment and case management service for people who need community care services (Recommendations 42).

The committee notes that population and health trends present challenges to the capacity of the community care workforce to meet future needs. An ageing and growing population with extended life expectancy will increase demand on Queensland Community Care services. The community services workforce is ageing, and there are challenges to recruiting and retaining an appropriately skilled workforce. The committee has recommended further work on workforce needs to meet future needs, and promotional work to highlight the value of care work (Recommendations 43 and 44).

Submitters described difficulties and delays in accessing equipment, and their experiences highlighted a lack of clarity about the equipment services provided by the Queensland Community Care Services and the Medical Aids Subsidy Scheme (MASS). Queensland Health acknowledged the importance of the services provided through the Department of Communities, Child Safety and Disability Services (Department of CCSDS) and Queensland Health's MASS being responsive and providing equipment in a timely manner.³⁰ The committee considers that information about equipment services and eligibility is inadequate, particularly in relation to the interface between Queensland Community Care Services and the MASS. The committee has recommended that the responsible Ministers collaborate to consider and implement an effective service model to provide equipment (Recommendations 45).

The committee was informed about some developments in assistive technology and ambient living and visited LifeTec to gain an understanding of some of the potential of technology to meet future community care needs. The committee considers that there is great potential for assistive technology to be used widely and successfully in community care to meet the growing need for person-centred care. While adoption rates have been low, there is potential for increased uptake with more promotion and use of familiar tools. The committee has recommended that the Minister for Communities, Child Safety and Disability Services consider providing resources for demonstration and pilot projects and research in the use of assistive technology in community care (Recommendations 46).

Carers – palliative and community care

Unpaid carers – usually family and friends – are the major providers of care and support for people who need palliative care or who have a disability or chronic illness. The committee has recommended a shift in emphasis to more home care, particularly for people who need palliative care. The challenges currently faced by carers will be magnified by this shift. The committee considers that adequate support and efficient structures for carer assistance will need to be put in place in tandem with other recommendations to improve palliative and community care provision.

Carers face a range of challenges, including lack of recognition or assessment of carer's needs, difficulties accessing information about services, difficulties maintaining employment, financial stress, inadequate respite from caring, lack of information about how to care safely (e.g. safe lifting) and negative impacts on carer health, and emotional and social well-being. The committee considers that the most important practical component of support for carers is access to flexible and adequately funded respite care. The committee has made a range of recommendations to better support carers (Recommendations 50 to 59).

Collaboration and co-operation between services

The terms of reference required the committee to consider opportunities for reform to improve collaboration and coordination between services. The committee heard evidence of problems that arise because of a lack of coordination, and notes that coordination problems are longstanding. The Department of Communities, Child Safety and Disability Services submitted that a key issue requiring attention is "greater clarity about the responsibility between community care and palliative care services."³¹ Queensland Health noted that the establishment of HHS is a potential driver of improvements in collaboration and co-ordination, and that the *Hospital and Health Boards Act 2011* requires HHS to undertake activities that are aimed at improved co-ordination between health services.³²

³⁰ Queensland Health, Submission no.35, p.14

³¹ DCCSDS, Submission no. 76, p.9

³² Queensland Health, *ibid.*, p.14

The committee has made a range of recommendations that it considers will, if implemented, contribute to improved collaboration and co-ordination, for example, information services. The committee heard that funding arrangements contribute to ‘silos’ in service delivery and can challenge the capacity to deliver services that meet people’s needs.³³

Common themes in evidence to the committee were the need to improve discharge planning and case management so that people do not ‘fall between the cracks’ and are not required to coordinate the sometimes complex network of services and agencies that they need. The committee has recommended that discharge planning be further examined to ensure that HHS provide timely discharge information to GPs, and where relevant to other health providers and RACFS (Recommendations 60).

Case management was considered by the committee as a way to deliver person-centred care in a complex service system. Witnesses told the committee that the case management component of care is generally not funded and non-government care providers sometimes fulfil this unfunded role. The committee notes that the case management role may be appropriately undertaken by a range of health or care providers, depending on the circumstances. The committee has recommended that Queensland Community Care Services be resourced to provide case management for clients who need services from multiple providers (Recommendation 61).

The committee also noted the potential of eHealth and technology to improve collaboration and co-ordination.

Segmentation of home and community care – State and Commonwealth responsibilities

The committee was asked to consider the segmentation of the former joint Home and Community Care (HACC) service system based on the age of the client, needs of the client, their carer and the providers. As noted above, Australian and Queensland government responsibilities for community care services changed in July 2012. The Commonwealth now has responsibility for HACC services for people aged 65 and over (50 and over for Aboriginal or Torres Strait Islander people), and Queensland has responsibility for Queensland Community Care Services for the younger age group.

Submissions received by the committee in August 2012, and in hearings in November 2012 raised concerns about the potential negative impacts of age segmentation of community care services. At that early stage in separation of the services, no evidence was available to the committee. The committee has recommended that the Minister for Communities, Child Safety and Disability Services report to the Parliament on the impacts of segmentation between July 2012 and June 2013 (Recommendations 62).

Evidence presented to the committee indicates there is uncertainty about the eligibility of palliative care patients to continue to receive Queensland Community Care Services, and eligibility is not clear. The committee has recommended that eligibility be clarified and clear guidance given to service providers (Recommendation 63).

³³ Glenys Webby, Director, Strategy and Service Planning, Blue Care, *Public Hearing Transcript*, 24 August 2012, p.24; Tam Shepherd, Chief Executive Officer, Greater Metro South Brisbane Medicare Local, *Public Hearing Transcript*, 22 August 2012, p.22; Margaret Deane, Aged and Disability Advocacy Inc., *Public Roundtable Discussion Transcript*, 28 November 2012, p.9

Recommendations

Chapter 6. Capacity, adequacy and effectiveness of palliative care services

Recommendation 1 – 24-hour state-wide telephone service 25

The committee recommends that the Minister for Health provide resources as soon as possible for a 24-hour state-wide palliative care telephone information, referral and support service, staffed by skilled nursing and allied health staff, and supported by an internet information service by, for example, incorporation into 13 QGOV.

Recommendation 2 – Participate in Palliative Care Outcomes Collaboration 27

The committee recommends that the Minister for Health:

- ensure that all public sector specialist palliative care services participate in and provide data to the Palliative Care Outcomes Collaboration (PCOC), and
- that Queensland Health publishes PCOC state-wide data on palliative care effectiveness.

The committee recommends that the Minister for Health:

- through the Chief Health Officer, encourage all private health facilities that provide specialist palliative care to participate in and provide data to PCOC
- encourage other specialist palliative care providers to participate in and provide data to PCOC.

Chapter 8. Palliative care for children and adolescents

Recommendation 3 – Children’s hospice 38

The committee recommends that the Minister for Health work with the Commonwealth Minister for Health to provide a children’s hospice in Queensland, with strong links with the specialist Paediatric Palliative Care Service at the Children’s Health Hospital and Health Service. The hospice should provide end-of-life care, respite care for children and adolescents with a life-limiting condition, information and advice on accessing services and bereavement counselling and support for families, including siblings.

Chapter 9. Aboriginal and Torres Strait Islander people – accessible and appropriate palliative care

Recommendation 4 – Aboriginal and Torres Strait Islander cultural training 42

The committee recommends that the Minister for Health ensure that service agreements, purchasing arrangements and funding for Hospital and Health Services which provide palliative care encourage the provision of targeted training in Aboriginal and Torres Strait Islander cultural issues and perspectives for staff who provide palliative care services.

Recommendation 5 – Promote awareness of Patient Travel Subsidy Scheme 43

The Minister for Health ensure that palliative care services and Aboriginal and Torres Strait Islander Health Services are made aware of the Patient Travel Subsidy Scheme and the situations in which financial assistance may be available to palliative patients and their families.

Recommendation 6 – Accommodation for Aboriginal and Torres Strait Islander people 44

The Minister for Health consider how accommodation for Aboriginal and Torres Strait Islander patients and their family and friends can be best provided during periods when patients are away from their usual residence to receive palliative care or other related treatment.

Chapter 10. Other cultural, language and lifestyle groups – accessible and appropriate palliative care

Recommendation 7 – Cultural training

48

The committee recommends that the Minister for Health ensure that service agreements, purchasing arrangements and funding for Hospital and Health Services which provide palliative care encourage the provision of targeted training in cultural issues affecting palliative care for staff who provide palliative care services.

Recommendation 8 – Needs based funding and interpreters

49

The committee recommends that the Minister for Health ensures that needs based funding to Hospital and Health Services for palliative care take account of the anticipated cost of interpreters in locations with a high proportion of people who speak a language other than English.

Recommendation 9 – Promote use of interpreters

49

The committee recommends that the Minister for Health direct Queensland Health to use service agreements and purchasing arrangements to ensure that Hospital and Health Services and non-government organisations that receive public funds use interpreters when needed.

Chapter 12. Palliative care in community settings

Recommendation 10 – Medicare benefits for GP palliative care

57

The committee recommends that the Minister for Health ask the Commonwealth Minister for Health to consider whether changes to the Medicare Benefits Schedule should be made for general practitioner consultations, home visits and residential aged care visits and associated travel costs for palliative care to support care in the home.

Recommendation 11 – Medication in community settings

61

The committee recommends that the Minister for Health consult with medical, nurse practitioner, RACF and pharmacy stakeholders and consider whether amendments to legislation are needed to facilitate more streamlined prescribing for patients in residential aged care facilities, and for palliative patients who receive care at home, including:

- ‘chart-based prescribing’ by medical practitioners
- any restrictions on nurse practitioners prescribing and supply of medications commonly used for pain management in palliative care, or supply of medications by nurses.

Recommendation 12 – Medication in residential aged care systems

62

The committee recommends that the Minister for Health work to ensure that public sector specialist palliative care services collaborate with residential aged care facilities (RACF) and general practitioners and Medicare Locals, to develop RACF medication systems that facilitate prompt access to needed medications for palliative patients, while ensuring the safety and security of medications and residents. This should include consideration of:

- Queensland Health as system manager including in service agreements or other instruments a requirement that Level 6 specialist palliative care services initiate action to implement suitable medication systems in collaboration with RACFs and organisations that represent general practitioners
- providing resources for palliative care services to develop suitable medication systems in collaboration with RACFs and general practitioners
- flexible medication models that are suitable for each location and consistent with legal requirements.

Recommendation 13 – Greater awareness of burial assistance **64**

The committee recommends that the Minister for Health ensure that all Hospital and Health Services with a palliative care service provide information on the burials assistance provided by the Department of Justice and Attorney-General to patients and carers when needed.

Recommendation 14 – Equipment loan services **65**

The committee recommends that the Minister for Health ensure that all Hospital and Health Services with a palliative care service operate, directly or through another provider, an accessible equipment loan service for home care to provide timely loan of palliative care equipment to patients who are cared for at home.

Recommendation 15 – Palliative care and ambulance services **69**

The committee recommends that the Minister for Police and Community Safety work with the Minister for Health to develop a protocol for ambulance officers if there is an expected death at home or in a residential aged care facility including:

- consultation with Hospital and Health Service palliative care services and ambulance officers
- examination of any legislative barriers to Queensland Ambulance Service (QAS) adopting a palliative approach for patients at home at the end of life
- consideration of wider acceptance by QAS of an Acute Resuscitation Plan or other documentation from a palliative care service or GP
- the provision of appropriate support by the QAS and ambulance officers to patients, carers and families before and after an expected death
- training in a palliative approach for ambulance officers.

Recommendation 16 – Hospices **71**

The committee recommends that the Minister for Health seek to provide resources for additional hospice beds in existing hospices and/or new hospices, based on an assessment of current and future needs and the viability of potential new hospices.

Chapter 13. Specialist palliative care services

Recommendation 17 – Specialist palliative care services – role and resources **74**

The committee recommends that the Minister for Health work toward ensuring that specialist palliative care services at the highest levels in the Queensland Health Clinical Services Capability Framework are resourced to provide a broad range of services in addition to direct care of patients with complex palliative care needs, particularly:

- consultation services to support other health providers including GPs and nurse practitioners
- visiting or in-reach services to residential aged care facilities
- 24-hour on-call services for patients cared for at home, potentially in collaboration with general practitioners and nurse practitioners
- training and support for home carers, and volunteer coordinators to train and support volunteers to provide in-home respite and carer support
- specialist bereavement counselling
- equipment loan services, and
- continuing education and capacity building for health professionals in palliative approaches.

Recommendation 18 – Specialist palliative care – formal partnerships with health providers **76**

The committee recommends that the Minister for Health ensure that Queensland Health, as system manager, investigate the most effective framework for formalised links between higher level specialist palliative care services and rural and regional services and GPs for the provision of specialist consultation services, and develop plans for formal partnerships in consultation with clinicians.

Chapter 14. Workforce capacity

Recommendation 19 – Nurse practitioner scholarships **80**

The committee recommends that the Minister for Health ensure that Queensland Health nurses are supported to undertake the study required to qualify as a nurse practitioner in palliative care by offering scholarships as soon as possible.

Recommendation 20 – Encouraging nurse practitioners into palliative care **80**

The committee recommends that the Minister for Health consult with stakeholders in nursing and nurse practitioner organisations to identify barriers and enablers to nurses undertaking study to qualify as nurse practitioners, and encouraging nurse practitioners to work in palliative care.

Recommendation 21 – Palliative care training for undergraduates **81**

The committee recommends that the Minister for Health work with the Centre for Palliative Care Research and Education to encourage Queensland universities to include palliative care in all undergraduate health training courses.

Recommendation 22 – Professional development in a palliative approach **82**

The committee recommends that the Minister for Health:

- consult with medical, nursing and allied health stakeholders to identify barriers and enablers to taking up existing professional development and training, including the Program of Experience in a Palliative Approach (PEPA)
- ensure that Queensland Health and Hospital and Health Services encourage the maximum possible uptake of PEPA training by GPs, nurses and other health providers.

Recommendation 23 – Training non-specialists in a palliative approach **83**

The committee recommends that the Minister for Health ensure that expansion of specialist palliative care services include the capacity to provide ongoing training and capacity building of the non-specialist health workforce to provide services using a palliative approach.

Recommendation 24 – Indigenous nurses – training pathways **84**

The committee recommends that the Minister for Health ensure that work is undertaken to:

- encourage and support Aboriginal and Torres Strait Islander enrolled nurses to upgrade their qualifications to registered nurse
- facilitate the recognition of prior learning for Aboriginal and Torres Strait Islander enrolled nurses who seek to upgrade their qualifications
- develop training pathways to encourage more Aboriginal and Torres Strait Islander people to commence qualifications in nursing.

Recommendation 25 – Palliative care training for Aboriginal Health Workers/Practitioners **85**

The committee recommends that the Minister for Health urge all Hospital and Health Services that employ Aboriginal Health Workers and Aboriginal Health Practitioners to consider offering to relevant staff the opportunity to undertake the tailored Program of Experience in a Palliative Approach.

Chapter 15. Telehealth, videoconferencing and eHealth

Recommendation 26 – Videoconferencing **90**

The committee recommends that the Minister for Health ensure that Queensland Health:

- consult with Hospital and Health Services and their specialist palliative care services to identify any barriers to increased use of the existing videoconference network for palliative care, and
- promote the use of videoconferencing in palliative care and consider developing incentives to promote greater use of videoconferencing for patient consultations, consultation with health providers to provide advice, build capacity and to provide training and professional development in palliative care.

Recommendation 27 – Telehealth and eHealth **91**

The committee recommends that the Minister for Health continue to support the development of national telehealth and eHealth initiatives that are suitable for use by all palliative health and care providers across public, community and private settings.

Chapter 16. Awareness and education – palliative care, dying and death

Recommendation 28 – National public awareness campaign **95**

The committee recommends that the Minister for Health work with his Commonwealth, state and territory ministerial counterparts to actively promote implementation of a national public awareness campaign as soon as practical to increase public understanding of:

- death as a normal part of living
- awareness of palliative care options, and
- the importance of advance care planning to facilitate choices about care.

Chapter 17. Advance care planning and Advance Health Directives

Recommendation 29 – Public awareness – advance care planning **100**

The committee recommends that the Minister for Health inform the Commonwealth Minister for Health that the committee supports the Recommendations 35 and 37 in the Senate Community References Committee report, Palliative care in Australia, that:

- the Australian Government fund a national public awareness campaign around advance care planning and directives, starting immediately, and expanding once a process of national harmonisation of advance care planning regulation has been undertaken
- the Australian Government increase the level of funding for the Respecting Patient Choices program to support development of training providers in several jurisdictions, significantly expanding the reach of the program in the aged care sector.

Recommendation 30 – Advance Health Directives **102**

The committee recommends that, given the uncertainties about current Queensland law governing advance health directives, the Government consider referring to the Health and Community Services Committee an inquiry into the law that applies to Advance Health Directives in Queensland.

Recommendation 31 – Advance Health Directives and doctors **103**

The committee recommends that the Minister for Health write to the Commonwealth Minister for Health to seek clarification of which Medicare Benefits Schedule items doctors may use for consultations to support a patient to complete an advance health directive.

Chapter 18. Resourcing and delivering needs-based and person-centred palliative care in Queensland

Recommendation 32 – State-wide palliative care strategy **109**

The committee recommends that the Minister for Health ensure that a state-wide palliative care strategy is developed as soon as possible to guide the development of palliative care planning, funding, development of specialist services, and improvement in the capacity of primary health and generalist health and care services to implement a palliative approach to care.

Recommendation 33 – State-wide palliative care strategy – key elements **109**

The committee recommends that the Minister for Health ensure that the state-wide palliative care strategy:

- is aligned with the National Palliative Care Strategy
- supports population and needs-based allocation of funding to maximise equity in the delivery of palliative care services, including equitable access for people with chronic conditions as well as those with cancer
- includes a staged approach to expansion of specialist palliative care services based on an assessment of palliative care needs for Queensland
- has a whole of system focus that promotes collaboration between acute hospital, specialist care and palliative care in the community
- acknowledges that most people would prefer home-based palliative care, and promotes the delivery of palliative care in the home when it is the patient's preference and it is possible to provide high quality care at home
- emphasises palliative care that is person-centred, based on needs, and allows patients and families to make choices about their care and where care is provided
- recognises the importance of bereavement care and support for family members, and significant others
- promotes case management approaches that use integrated electronic health records which link with other care providers and general practitioners
- aligns with the Clinical Services Capability Framework that applies to Hospital and Health Services and licensed private health facilities
- promotes planning by Hospital and Health Services to provide palliative care services in a range of settings including specialist consultation and liaison services to support palliative care in the home and residential aged care facilities
- promotes integrated care that includes advance care planning, and
- includes timeframes for implementation of the main components of the strategy.

Recommendation 34 – Clinical Services Capability Framework – review of service levels **110**

The committee recommends that the Minister for Health ensure that the self-assessed levels of palliative care services in the Clinical Services Capability Framework are externally reviewed as soon as possible and adjusted if necessary to accurately map the existing levels of service provision and inform quality improvement and planning of service development and expansion.

Recommendation 35 – Population-based palliative care needs assessment **110**

The committee recommends that the Minister for Health ensure that a rigorous Queensland population-based palliative care needs assessment is completed as soon as possible, taking account of geography, demographics and factors relevant to the provision of palliative care, to provide a basis for service planning and future funding.

Recommendation 36 – Planning and funding benchmarks **111**

The committee recommends that the Minister for Health ensure that Queensland Health implement a review of planning benchmarks by population as soon as possible as a basis for decisions about the expansion, establishment and funding of additional palliative care services. The review should include consideration of resourcing levels for the range of functions required of specialist palliative care services.

Recommendation 37 – Reporting on funding **112**

The committee recommends 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.

Recommendation 38 – Separate palliative care from ‘subacute’ funding **112**

The committee recommends 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 funding should be separated from ‘subacute’ funding.

Recommendation 39 – National funding **113**

The committee recommends that the Minister for Health write to the Commonwealth Minister for Health to:

- support the Senate committee’s Recommendation No. 3 that the Independent Hospital Pricing Authority (IHPA) establish a palliative care advisory committee to advise on appropriate costing of palliative care services
- propose that the IHPA 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.

Recommendation 40 – Specialist palliative care service resourcing and delivery **115**

The committee recommends that the Minister for Health ensure that Queensland Health plans for and supports implementation of accessible specialist palliative care across Queensland and that, in its system manager role, uses service agreements and purchasing arrangements to ensure that Hospital and Health Services:

- deliver more palliative care services in the home and community
- implement the Clinical Services Capability Framework
- make constructive links between specialist palliative care services and general health services to ensure that specialist palliative care consultation services are readily accessible to all Hospital and Health Service facilities
- implement case management
- ensure discharge planning is carried out, and
- deliver specialist palliative care services that:
 - o develop greater capacity to deliver care in the home and in residential aged care facilities, so that patient preferences are met and the costs associated with unwanted and unnecessary admission are reduced
 - o provide 24-hour telephone and home visiting support to existing clients
 - o provide specialist consultancy and liaison services to other public sector facilities and to general practitioners
 - o adopt models of care that use specialist nurse practitioners
 - o provide training for palliative care specialists to build capacity to meet increasing needs for palliative care
 - o provide bereavement counselling and
 - o support the provision of equipment and training for care in the home.

Recommendation 41 – Evaluation and best practice **116**

The committee recommends that the Minister for Health ensure that:

- innovative models of palliative care in Queensland are evaluated, so that success factors can be identified to contribute to practice and quality improvement
- Queensland Health provide information and guidance to Hospital and Health Services about best practice delivery of person-centred palliative care, and
- a program of research is established and resourced to evaluate models of palliative care provision, standards and outcomes.

Chapter 19. Capacity, adequacy and effectiveness of community care services

Recommendation 42 – Queensland Community Care – information, referral, assessment 119

The committee recommends that the Minister for Communities, Child Safety and Disability Services, in consultation with the Minister for Science, Information Technology, Innovation and the Arts, ensure that a seamless information, assessment and referral service is implemented to assist potential Community Care clients to access services. The committee recommends that the Minister ensures that the model:

- builds on the outcomes of the Community Access Point trial
- links consumers to a person with current regional or local knowledge of relevant services
- provides information about Community Care and other relevant services
- undertakes eligibility screening, initial assessment, referral and co-ordination
- employs effective referral and assessment, which minimises the impost on clients and does not require multiple assessments
- promotes consumer choice and responsive service provision
- provides case management for clients who receive services from multiple providers, and
- is supported by up-to-date web-based information.

Recommendation 43 – Community care workforce 123

The committee recommends that the Government consider implementing a promotional campaign aimed at changing public perceptions of community care and its workforce. A campaign should aim to promote and highlight:

- the social value of caring for people
- the size of the community care sector and its contribution to Queensland's economy, and
- the range of jobs and career pathways available in community care.

Recommendation 44 – Research and planning for community care workforce capacity 123

The committee recommends that the Government commission research on the community care workforce in Queensland to:

- provide an assessment of future community care workforce needs to meet expected increases in need for services, taking account of the ageing workforce and population, and
- develop strategies to ensure that the community care workforce has capacity to meet future needs, including active workforce planning, recruitment, training pathways and workforce retention.

Chapter 20. Improving service adequacy, effectiveness and efficiency – needs-based and person-centred services

Recommendation 45 – Equipment services 127

The committee recommends that the Minister for Health and the Minister for Communities, Child Safety and Disability Services collaborate to consider and implement the most effective service model to provide equipment, including:

- consideration of a single integrated equipment service
- clear public information about eligibility criteria and how to apply for assistance with equipment, and
- timely provision of equipment to support people at home.

Recommendation 46 – Assistive technology demonstration and pilot projects **128**

The committee recommends that the Minister for Communities, Child Safety and Disability Services consider providing resources for demonstration and pilot projects and research in the use of assistive technology in community care. Those projects should have the potential to:

- develop effective models of care that integrate assistive technology, including specific applications for people in rural and remote areas
- increase community awareness and knowledge of the benefits of assistive technology
- reduce social isolation
- reduce the complexities associated with assistive technology applications
- promote innovation
- use inter-disciplinary models of care, and
- measure the impact of assistive technologies to provide evidence of effectiveness and promote transfer of knowledge to other service providers.

Chapter 21. Carers

Recommendation 47 – Data on carers **132**

The committee recommends that given the importance of access to reliable data for policy development and planning the Government ask the Government Statistician and the Office of Economic and Statistical Research to ensure that data on carers in Queensland and the hours they work are readily available to government agencies, including data that may be available via Australian Government collections.

Chapter 22. Supporting carers

Recommendation 48 – Service providers to consult with carers **136**

The committee recommends that the Minister for Communities, Child Safety and Disability Services ensure that service providers are required to consult with carers about the delivery of services.

Recommendation 49 – Carer involvement in policy development **137**

The committee recommends that the Minister for Communities, Child Safety and Disability Services ensure that policy development and implementation supports the role of carer by consulting with carer organisations on the development of any legislation, policy or program guidelines.

Recommendation 50 – Information for carers **137**

The committee recommends that the Minister for Communities, Child Safety and Disability Services, in developing the information service recommended in Recommendation 42, specifically include information to assist carers.

Recommendation 51 – Carer’s needs assessment – Queensland Community Care **139**

The committee recommends that the Minister for Communities, Child Safety and Disability Services direct the Department of Communities, Child Safety and Disability Services to include in service agreements with providers of Queensland Community Care Services or in guidelines for service providers a requirement to individually assess a carer’s needs.

Recommendation 52 – Carer’s needs assessments – palliative care **139**

The committee recommends that the Minister for Health ensure that Queensland Health’s service agreements with Hospital and Health Services (HHS) require specialist palliative care services to assess carer needs and that any service agreements between a HHS and service provider include a requirement to assess carer needs.

Recommendation 53 – Carer’s respite **140**

The committee recommends that the Minister for Communities, Child Safety and Disability Services, in consultation with the Minister for Health, develop an adequate, single program of respite support for carers that provides for streamlined access based on flexible options for carers for use across a range of respite types (e.g. in-home and centre-based, both day and overnight).

Recommendation 54 – Carers – workplace flexibility **142**

The committee recommends that the Queensland government work toward implementation in all Queensland government and local government workplaces, integrated carer strategies, and provide information and support services to carers, offer flexible hours and leave arrangements, undertake job redesign to accommodate caring commitments and implement employment re-entry strategies during and after caring responsibilities.

Recommendation 55 – Carers support – national **143**

The committee recommends that the Government raise the importance of recognising carers’ needs for flexibility in the workplace with the COAG Select Council on Workplace Relations and encourage implementation of additional strategies to support employed carers.

Recommendation 56 – Specialist bereavement services **143**

The committee recommends that the Minister for Health ensure that Hospital and Health Service service agreements include recognition that quality palliative care services, particularly in higher level services (in the Clinical Services Capability Framework), should include specialist bereavement services.

Recommendation 57 – Counselling services for carers **143**

The committee recommends that the Minister for Communities, Child Safety and Disability Services ensure that relevant service agreement contracts with service providers include the provision of counselling services for carers.

Recommendation 58 – Carers – guidance and training on how to care safely and self-care **144**

The committee recommends that the Minister for Communities, Child Safety and Disability Services ensure that relevant agreements with service providers and service guidelines require providers to offer practical training and guidance about how to care safely and on self-care for carers.

Recommendation 59 – Specialise palliative care services – volunteer co-ordinators **144**

The committee recommends that the Minister for Health ensure that appropriate mechanisms are in place to ensure that Level 5 and 6 specialist palliative care services (in the Clinical Services Capability Framework) are resourced to engage a person to train and coordinate volunteers to provide services such as in-home social contact and respite for carers.

Chapter 23. Improving collaboration and co-ordination

Recommendation 60 – Discharge planning **150**

The committee notes that inadequate discharge planning can contribute to unplanned admissions to hospital, that discharge planning should commence at admission and recommends that the Minister for Health:

- encourage Hospital and Health Services (HHS) to review and improve discharge planning in consultation with GPs, residential aged care facilities, community care and Home and Community Care service providers, and
- ensure that HHS provide timely discharge information to patients’ GPs, and where relevant other health providers, community service providers and residential aged care facilities.

Recommendation 61 – Case management **150**

The committee recommends that the Minister for Communities, Child Safety and Disability ensure that Queensland Community Care Services are resourced to provide case management for those clients who need services from multiple service providers, including health services.

Recommendation 62 – Separation of HACC and Queensland Community Care **155**

The committee recommends that the Minister for Communities, Child Safety and Disability Services monitor the impact of the separation of Commonwealth and State responsibilities for home and community care services by age in July 2012 and report to the Parliament by December 2013, particularly on:

- whether continuity of service delivery was maintained for clients who reached age 65 (or age 50 for Aboriginal or Torres Strait Islander people) between 1 July 2012 and 30 June 2013
- any increase in the administrative and reporting requirements on funded service providers in 2012–13, particularly those that receive funds from both the Queensland Community Care program and the Commonwealth HACC program.

Recommendation 63 – Palliative care and Queensland Community Care **156**

The committee recommends that the Minister for Communities, Child Safety and Disability Services clarify whether people who receive palliative care services at home are eligible to receive Queensland Community Care Services and ensure that service providers are given clear guidance on eligibility.

Committee comments

Committee comment – Specialist palliative care services – consultation and shared care 56

The committee considers that the provision of consultation and shared care services by specialist palliative care services is essential to facilitating quality palliative care in the community, in line with most people's preferences. It is expected that additional resources will be required to ensure that specialist palliative care services can provide the required level of consultancy and shared care to support accessible palliative care for all Queenslanders.

The committee believes that improved planning and implementation of formalised and systematic arrangements for specialist consultation and liaison services, and increased use of telehealth consultations can improve access to specialist palliative care consultancy and advice to GPs and other health providers.

Specialist palliative care services should have the capacity to provide consultation by telephone and videoconference with smaller palliative care services, other hospitals, general practitioners and residential aged care facilities. The committee believes that an investment in specialist palliative care services to provide consultation services and support home-based care could be offset by a reduction in acute hospital costs from unnecessary and unwanted hospital admissions. The committee's recommendations about specialist palliative care services are in Chapter 13.

Committee comment – Electronic health records 62

The potential benefits of a system of electronic health records accessible to all clinicians and carers and with appropriate security and privacy safeguards have been much discussed in recent years. The committee considers that further development of a national system of electronic health records is critically important. The committee encourages the Minister to support further development of electronic health records that can be used across public and private health and care services to improve co-ordination of health care, including palliative care.

Committee comment – Encourage Hospital in the Home 66

The committee considers that Hospital in the Home (HITH) initiatives have the potential to deliver high levels of patient and carer satisfaction, provided adequate support exists for carers. Queensland Health should encourage use of palliative care Hospital in the Home as a substitute for acute inpatient care. The committee notes that the economic analysis of HITH does not appear to have compared costs for palliative care.

Committee comment – Hospices 71

The committee believes that more hospice beds are needed in Queensland, to provide inpatient care for the dying in a home-like and cost effective setting. Given the current distribution of hospices, there is likely to be a significant need for additional inpatient hospice care outside the south-east of the state. The committee has recommended that the Minister for Health consider the need for more hospice beds in existing hospices, and wider distribution of hospices, as part of assessing population based needs for palliative care.

The committee has also recommended the development of a state-wide strategic plan, and research to develop a population and needs-based model for planning and funding of palliative care services (see Chapter 18). Funding of additional hospice beds and/or hospices should be based on needs, along with assessment of viability of a hospice.

Introduction

Role of the committee

The Health and Community Services Committee (the committee) was established by resolution of the Legislative Assembly on 18 May 2012, and consists of government and non-government members.

The committee is responsible for examining legislation, considering public accounts and public works matters (within its portfolio areas) and considering and reporting on matters referred to it by the Legislative Assembly. The portfolio areas for which the committee is responsible are health, communities, child safety, disability services, national parks, recreation, sport, racing, Aboriginal and Torres Strait Islander affairs and multicultural affairs. The committee also has responsibility for monitoring and reviewing the performance of three statutory bodies.

Section 92 of the *Parliament of Queensland Act 2001*³⁴ provides that a portfolio committee is responsible for dealing with an issue referred to it by the Assembly, and may consider the matter, report on it and make recommendations to the Assembly.

Terms of reference

The committee recognised that the terms of reference (see page xviii) were broad and could be interpreted to include examination of almost all disability and aged care services ('frail care services') as well as health services to prevent and treat a broad range of chronic health conditions ('chronic care services'). A broad interpretation of the terms of reference would have encompassed a significant part of both the health and disability systems, along with aged care services for which the Commonwealth has responsibility. The committee instead decided to focus its inquiry on the capacity, future needs, effectiveness, efficiency and adequacy of palliative care services for adults and children, and community and home care services, whether those services were needed because of frailty, the consequences of a chronic condition or a disability. The committee recognised that examination of opportunities for reform to improve collaboration and co-operation between services could include examination of reform opportunities relevant to a broader range of health services, disability services and community care services.

The services within the inquiry terms of reference are the responsibility of the Minister for Health and the Minister for Communities, Child Safety and Disability Services.

The Senate Community Affairs References Committee undertook an inquiry into palliative care in Australia between November 2011 and October 2012. The Senate Committee's report, *Palliative care in Australia*, is referred to in this report.

The committee's processes

The inquiry terms of reference were advertised in the Courier Mail and on the committee's website in June 2012, calling for submissions. The committee wrote to stakeholder organisations to inform them of the inquiry and to invite submissions. An Issues Paper published by the committee contained information about the matters that would be examined, and was published on the committee's website and distributed to stakeholders. Seventy-six submissions were received. A list of submissions is in Appendix A.

Public hearings were held in Brisbane on 22 and 24 August 2012, in Mount Isa on 4 February 2013 and in Townsville on 5 February 2013. Two private hearings were also held in Brisbane in August 2012. A list of people who gave evidence in public hearings is in Appendix B and transcripts are available on the committee's website at www.parliament.qld.gov.au/hcsc.

³⁴ Available at: <http://www.legislation.qld.gov.au/LEGISLTN/CURRENT/P/ParliaQA01.pdf>

Two public roundtable discussions were held in Brisbane in November 2012 to gain further evidence and understanding of specific issues that had arisen in submissions and hearings. The committee invited stakeholders with relevant experience to participate in structured discussions with the committee. The committee engaged Mr Mark Hunter to facilitate the discussions. Transcripts are published on the committee's website.

Private roundtable discussions were also held in February 2013 in Mount Isa, with the Royal Flying Doctor Service to gain an understanding of issues in remote communities, and with the Townsville Aboriginal and Islander Health Service.

In addition to the evidence provided in submissions, hearings and roundtable discussions, the committee has drawn on published reports and journal articles, and the report of the Senate Community Affairs Reference Committee,³⁵ to assist it in its deliberations on the terms of reference.

Structure of this report

While the committee's terms of reference were broad in scope, most of the evidence presented to the committee was about palliative care, compared to the limited evidence about community care. The report reflects that imbalance in the evidence.

The first two Parts of the report provide background about government policy and services in palliative care, community care, and support for carers. **Part 1 Commonwealth and State roles and policy context** (Chapters 1 to 3) outlines policy and funding responsibilities of both the State and Commonwealth in palliative care, community care, and carers.

Part 2 Current services in Queensland (Chapters 4 and 5) gives a brief overview of the current palliative care and community care services in Queensland, based on submissions, evidence from hearings and information that was readily accessible. Palliative care services are described in Chapter 4, including an overview of services and a short summary of the Queensland Health *Clinical Services Capability Framework for Public and Licensed Private Health Facilities*, and the location of Hospital and Health Service palliative care services. Chapter 5 gives a brief description of Queensland Community Care Services, which is the state component of the former Home and Community Care Program.

Part 3 Palliative care in Queensland – future directions (Chapters 6 to 19) represents the main part of this report, and addresses the terms of reference about current capacity and future needs for services, and their effectiveness and efficiency. It outlines the evidence presented to the committee and the committee's views and recommendations for future directions for palliative care services in Queensland. Chapters 6 to 11 discuss the capacity and adequacy of palliative care services generally, projections of future need, and issues relevant to specific population groups, including children, and people in rural and regional areas.

Chapters 12 (*Palliative care in community settings*) and 13 (*Specialist palliative care services*) describe important elements of the committee's views on future directions for palliative care. In summary, the committee supports greater emphasis on palliative care at home (if it is a person's preference and is possible). The committee recognises that most palliative care can be provided effectively, with specialist support, by general practitioners (GPs) and other health and care providers who are not palliative care specialists. Those non-specialist health and care providers need specialist palliative care services to provide consultancy and advice, training, 24-hour services and ongoing support to deliver high quality care in the community. Chapter 12 touches on the role of carers, which is discussed in Part 5.

³⁵ Senate Community Affairs References Committee (Senate Committee inquiry), *Palliative care in Australia*, 2012, Canberra, available at http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=clac_ctte/completed_inquiries/2010-13/palliative_care/report/index.htm

In Chapters 14 (*Workforce capacity*) and 15 (*Telehealth, videoconferencing and eHealth*) some of the elements of building and maintaining the capacity to deliver palliative care services are discussed.

Community awareness and capacity to talk about death, dying and palliative care are discussed in Chapter 16 (*Awareness and education*). The closely related issues of advance care planning and Advance Health Directives are discussed in Chapter 17 (*Advance care planning and Advance Health Directives*).

Part 4 *Community care and home care services in Queensland – future directions* discusses issues relevant to the terms of reference about capacity, future needs and the effectiveness of community care services. The brief discussion in Chapters 19 (*Capacity, adequacy and effectiveness of community care services*) and 20 (*Improving service adequacy, effectiveness and efficiency*) reflects the limited evidence about community care services received by the committee.

In **Part 5** *Carers*, the critical importance of support for carers is discussed. A shift to more care in the home would place additional burdens on carers, and success would require adequate support for carers.

The two final parts of the committee's terms of reference are discussed in **Part 6** *Collaboration and co-operation between services*, and **Part 7** *Segmentation of home and community care*.

Part 1 Commonwealth and State roles and policy context

Chapter 1. Palliative care

1.1 The National Healthcare Agreement

A range of national agreements define the objectives, outcomes, outputs, performance indicators, and the roles and responsibilities of the Commonwealth and the states and territories for the delivery of services across a particular sector. These various agreements are made under the Intergovernmental Agreement on Federal Financial relations.³⁶

Under the National Healthcare Agreement, the Commonwealth is responsible for funding access to private medical care, pharmaceuticals and private health insurance, education of health professionals, health services for eligible veterans, residential, community and flexible aged care services, the purchase of vaccines under national immunisation arrangements and community-controlled Aboriginal and Torres Strait Islander primary healthcare.³⁷ The states and territories are responsible for funding community health, capital infrastructure and service planning, ambulance services, food safety and regulation, environmental health and disability services.³⁸

The Commonwealth and the states and territories are jointly responsible for funding:³⁹

- public hospitals
- public health activities
- mental health services
- sub-acute care (including rehabilitation, palliative care, geriatric evaluation and management, and psychogeriatric care)⁴⁰
- Aboriginal and Torres Strait Islander health services
- health research
- health workforce training
- emergency responses, and
- blood and blood products.

1.2 National health reform

Health costs are increasing due to Australia's ageing population, rising chronic disease incidence, new technologies and higher consumer expectations. Projections of costs and revenues indicated that states and territories would not be able to continue to cover the funding required under the existing health sector structures.

In April 2010, the Council of Australian Governments (COAG), with the exception of Western Australia, endorsed the National Health and Hospitals Network (NHHN) Agreement and a heads of agreement on national health reform.

The agreement to establish an NHHN proposed significant changes to the basic structures of the health system to make them more responsive to the needs of local communities. The agreed reforms were also aimed at ensuring much greater transparency of the health funding arrangements. The

³⁶ Standing Council on Federal Financial Relations, *Intergovernmental Agreement on Federal Financial Relations*, accessed 23 January 2013 from

http://www.federalfinancialrelations.gov.au/content/intergovernmental_agreements.aspx

³⁷ Council of Australian Governments (COAG), *National Healthcare Agreement 2012*, p.A-8, available at

<http://www.federalfinancialrelations.gov.au/content/npa/healthcare/national-agreement.pdf>

³⁸ COAG, *ibid.*, p.A-7

³⁹ COAG, *ibid.*, p.A-6

⁴⁰ Australian Institute of Health and Welfare (AIHW), *National Health Data Dictionary 2012 – version 16*, 2012, Canberra, accessed 24 January 2013 from <http://www.aihw.gov.au/publication-detail/?id=10737422826>

Australian Government agreed to take majority funding responsibility across Australia's health and hospitals system, with governance and management of local health and hospital services devolved to the local level.⁴¹ New funding for health services was provided under the agreement in June 2010 and the Australian Government began the process of establishing Medicare Locals (an element of the agreed arrangements).

In February 2011, a revised reform agenda was agreed by the Commonwealth and all states and territories and, in July 2011, the NHHN Agreement was superseded by the National Health Reform Agreement.⁴² The National Health Reform Agreement put greater focus on a more equal sharing of responsibility for the funding of the growth in costs of public hospital services in the future and a more direct and simplified funding of public hospital services, based on the efficient price of providing those services. Rather than separate funding authorities in each state and territory, the agreement establishes a single National Health Funding Pool, with an independent administrator to oversee both the Commonwealth and state and territory funding of the public hospital system.⁴³

Queensland Health notes that the health reforms "bring new opportunities at the local Hospital and Health Service level, for all health care providers (specialist and generalist health providers, community service providers as well as Medicare Locals) to work together to better coordinate the delivery of palliative care services for people who need it, where possible in their setting of choice".⁴⁴

1.3 National partnership agreements

In addition to national agreements on health care and health reform, a range of national partnership agreements (NPAs) between the Commonwealth and the states and territories provide a mechanism to support the delivery of specified outputs or projects, and facilitate reforms or financially reward jurisdictions that deliver on nationally significant reforms.

Under NPAs, facilitation payments are used to assist a state or territory to lift standards of service delivery or to encourage the states and territories to agree to implement ambitious reforms. Reward payments are provided to the states and territories which deliver reform progress measured against performance benchmarks detailed in the agreement and assessed by the COAG Reform Council. NPAs may include implementation plans which outline the specific performance benchmarks that trigger payments from the Commonwealth.

The NPA on Improving Public Hospital Services includes additional Commonwealth funding for subacute beds in public hospitals. COAG will review (by December 2013) whether the Commonwealth funding under the agreement should continue.⁴⁵ Under this agreement, Queensland has the flexibility to determine the mix of subacute service types and regional distribution of beds and services. Over the period 2010–11 to 2013–14, 10 palliative care beds have been allocated to Queensland's Queen Elizabeth II hospital, 10 to Redlands and four (4) for paediatric palliative care at the Royal Children's Hospital. Ipswich received funding for non-admitted subacute care services.⁴⁶

⁴¹ A *National Health and Hospitals Network for Australia's Future: Delivering the Reforms*, 2010, Canberra, p.12, available at [http://www.yourhealth.gov.au/internet/yourHealth/publishing.nsf/Content/DeliveringTheReforms/\\$FILE/DeliveringTheReforms.pdf](http://www.yourhealth.gov.au/internet/yourHealth/publishing.nsf/Content/DeliveringTheReforms/$FILE/DeliveringTheReforms.pdf)

⁴² COAG, *National Health Reform Agreement*, 2011, p.4, available at http://www.federalfinancialrelations.gov.au/content/npa/health_reform/national-agreement.pdf

⁴³ Department of Health and Ageing (DOHA), *Frequently Asked Questions for the Health Sector – Why do we need another health agreement? Didn't we have a health care agreement in 2010?*, accessed 23 January 2013 from <http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/nhra-faq-healthprof#another>

⁴⁴ Queensland Health, Submission no. 35, p.3

⁴⁵ COAG, *The National Health Reform Agreement – National Partnership Agreement on improving public hospital services*, p. 11, available at http://www.federalfinancialrelations.gov.au/content/npa/health_reform/national-workforce-reform/national_partnership.pdf

⁴⁶ Senate Community Affairs References Committee, *Answers to Questions on Notice, Health and Ageing portfolio, Additional Estimates 2011–12*, 15 February 2012, Question E12–143, available at http://www.apf.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=clac_ctte/estimates/add_1112/index.htm

1.4 Activity Based Funding

The National Health Reform Agreement includes a commitment to move to Activity Based Funding (ABF) with an independently set 'national efficient price' for those public hospital services.⁴⁷ The recently released Commission of Audit report notes that Queensland was 11 per cent less efficient than the nationally efficient price for inpatient services in 2009-10. The report's consideration of casemix data for hospitals indicates that Queensland's cost of service is 8.2 per cent above the Australian average, higher than all other mainland states.⁴⁸

During 2012-13, Queensland will transition to the national model developed by the Independent Hospital Pricing Authority (IHPA). For the transition years of 2012-13 and 2013-14, total Commonwealth funding is limited to the level prescribed in the 2008 National Health Care Agreement. From 2014-15 onwards, the Commonwealth will be required to pay defined percentages of the growth in public hospital services.⁴⁹

Queensland continues to be responsible for system-wide planning of the required range, type and volume of public hospital and health services in Queensland. Neither the Australian Government (through its funding role), nor the IHPA (through its role in price determination), has any direct role in determining what services will be funded locally or the level at which services should be provided. As specified in the National Health Reform Agreement, these decisions are primarily shared between the Queensland government and the Hospital and Health Services (HHSs).⁵⁰

The pricing framework for Australian Public Hospital Services announced by the IHPA in May 2012 determines that in-scope non-admitted services do not have to be provided on the campus of a public hospital. Non-admitted services, including palliative care, can be provided at a hospital, in the community, or in a person's home. Palliative care services are therefore in-scope and eligible for Commonwealth funding.

The IHPA notes that the pricing framework ensures that decisions about the scope of funded public hospital services should not create an incentive for services to be provided in a particular setting. It affirms the roles of states and territories as system managers responsible for planning how best to organise and deliver public hospital services for their populations and for HHSs with respect to local needs. The pricing framework also recognises that decisions about where public hospital services will be provided for individual patients are clinical decisions involving patients and health professionals.⁵¹

1.5 Queensland Health and Hospital and Health Service roles

Queensland Health has oversight of the public health system to promote equitable access to services and to ensure health services across Queensland meet consistent clinical standards. Queensland Health also undertakes planning, funding and delivery of teaching, training, research and major capital works.⁵²

The 17 HHSs in Queensland operate as independent statutory bodies overseen by Hospital and Health Boards. Their role is to deliver hospital and health services in their particular area, or state-

⁴⁷ Queensland Government, *State Budget 2012-13 – Budget Paper 5: Service Delivery Statements – Queensland Health*, p.5, available at <http://www.budget.qld.gov.au/budget-papers/2012-13/bp5-gh-2012-13.pdf>

⁴⁸ Queensland Government, *Queensland Commission of Audit Final Report – February 2013*, Vol.3, pp.3-24 and 3-25, available at <http://www.commissionofaudit.qld.gov.au/reports/final-report.php>

⁴⁹ Independent Hospital Pricing Authority (IHPA), *IHPA and Activity Based Funding*, accessed 24 January 2013 from <http://www.palliativecare.org.au/Portals/46/EVENTS/Tony%20Sherbon%20Presentation.pdf>

⁵⁰ Health Policy Solutions, in association with Casemix Consulting and Aspex Consulting, *Activity based funding for Australian public hospitals: Towards a Pricing Framework*, 2011, p.14, accessed 23 January 2013 from [http://www.ihoa.gov.au/internet/ihoa/publishing.nsf/Content/EB8EFD07DF85BC70CA25798300033BE1/\\$File/IHPA%20Draft%20Pricing%20Framework_long%20version.pdf](http://www.ihoa.gov.au/internet/ihoa/publishing.nsf/Content/EB8EFD07DF85BC70CA25798300033BE1/$File/IHPA%20Draft%20Pricing%20Framework_long%20version.pdf)

⁵¹ IHPA, *Pricing Framework for Australian Public Hospital Services*, 2012, p.11, available at [http://www.ihoa.gov.au/internet/ihoa/publishing.nsf/content/6F3568CF33E77887CA257A16000D168C/\\$File/PricingFramework.pdf](http://www.ihoa.gov.au/internet/ihoa/publishing.nsf/content/6F3568CF33E77887CA257A16000D168C/$File/PricingFramework.pdf)

⁵² Queensland Government, *State Budget 2012-13*, p.4

wide in the case of the Children's HHS.⁵³ Hospital and Health Boards commenced operation on 1 July 2012 and Queensland Health's corporate office took the role of system manager.⁵⁴

Queensland Health purchases health services from the HHSs under a service agreement with each HHS.⁵⁵ The service agreement broadly defines the hospital services, health services, teaching, research and other services that are to be delivered by the HHS and the funding to be provided for the delivery of those services. The service agreement also sets out how Queensland Health will manage the performance of HHSs.⁵⁶

As system manager, Queensland Health may use financial incentives and purchasing models to influence HHS to adopt new models of care. HHSs are accountable to the Minister for Health and their local community. They have the flexibility to determine how services are provided in order to meet local needs and priorities.⁵⁷

Current service agreements cover the period from 1 July 2012 to 30 June 2013. The 2012–13 service agreements include a Healthcare Purchasing Framework, in line with the requirements of the National Health Reform Agreement. The *Hospital and Health Services Performance Framework 2012–13* allows for the review, assessment and reporting of performance. It provides a transparent, rules-based process for monitoring performance against clearly identified targets and includes a protocol for managing performance issues, including poor performance. The current purchasing framework also recognises high performance.⁵⁸

1.6 National Palliative Care Strategy

The National Palliative Care Strategy was initially released in 2000 to guide planning and policy development for palliative care. During 2010, after extensive consultations, the strategy was updated to take account of developments in policies and practices. The current strategy was endorsed by the Australian Health Ministers' Conference in November 2010 and released in February 2011.⁵⁹

The strategy provides a national framework for directing palliative care policy, planning and services towards common and agreed goals. The national framework guides the Australian Government and state and territory governments in policy development and service delivery. The strategy is also intended to assist co-ordination between the Australian Government's National Palliative Care program and the states and territories, which provide most palliative care services.⁶⁰

The strategy focuses effort on four goal areas: awareness and understanding, appropriateness and effectiveness, leadership and governance and capacity and capability. It includes goal statements, objectives, action areas and some suggested measures of success.

The specific goals under the current strategy are to:

- significantly improve the appreciation of dying and death as a normal part of the life continuum (*Goal – awareness and understanding*)
- enhance community and professional awareness of the scope of, and benefits of, timely and appropriate access to palliative care services (*Goal 2 – awareness and understanding*)

⁵³ Queensland Government, *ibid.*, p.4

⁵⁴ Queensland Government, *ibid.*, p.1

⁵⁵ Queensland Government, *ibid.*, p.5

⁵⁶ Queensland Health, *Service Agreements*, accessed 18 January 2013 from http://www.health.qld.gov.au/hhsserviceagreement/html/service_agreements.asp

⁵⁷ Queensland Government, *ibid.*, p.4

⁵⁸ Queensland Health, *ibid.*, p.4

⁵⁹ DOHA, *National Palliative Care Strategy 2010*, p.4

⁶⁰ Minister for Mental Health and Ageing, *National Palliative Care Strategy Released*, Media Release, 10 February 2011, available at [http://www.health.gov.au/internet/ministers/publishing.nsf/Content/6FF9864F1D27DCCACA2578320081050D/\\$File/mb020.pdf](http://www.health.gov.au/internet/ministers/publishing.nsf/Content/6FF9864F1D27DCCACA2578320081050D/$File/mb020.pdf)

- ensure appropriate and effective palliative care is available to all Australians based on need (*Goal – appropriateness and effectiveness*)
- support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches (*Goal – leadership and governance*)
- build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care (*Goal – capacity and capability*).⁶¹

1.7 The National Palliative Care Program

1.7.1 Aims

The National Palliative Care Program aims to improve access to, and the quality of, palliative care by ensuring that quality of life is maintained for people with a terminal illness and support provided for them to die with dignity in the setting of their choice. The national program provides grants to local groups, health and aged care providers and church and charitable organisations to support patients and their families receiving palliative care.

1.7.2 Access to palliative care medicines

To increase access to palliative care medicines in the community the Palliative Care Clinical Studies Collaborative manages multi-site clinical drug trials to gather the scientific evidence required to register palliative care medicines on the Australian Register of Therapeutic Goods and possible listings on the Pharmaceutical Benefits Scheme.

1.7.3 Education and training for the healthcare workforce

Education and training for the healthcare workforce in the palliative approach is supported by the national program through:

- Program of Experience in the Palliative Approach (PEPA), a work placement training program for health professionals in a specialist palliative care service of their choice
- distribution of guidelines for a palliative approach in residential aged care, development of guidelines for a palliative approach for aged care in the community setting and development of pain management guidelines for residential aged care
- development of Certificate III and IV units of competency in the palliative approach, including a related teaching resource
- development of, and support for implementation of, the Palliative Care Curriculum for Undergraduates (PCC4U), resources to enable palliative care approaches and techniques to be incorporated into medical, nursing and allied health undergraduate curricula, and
- implementation of the Respecting Patient Choices program, a comprehensive advance care planning training program for health professionals that aims to ensure patients' choices about their end of life care are respected.

1.7.4 Research, analysis and information

The national program funds research, analysis and information relating to the provision of palliative care services. The program funds:

- the Australian Palliative Care Outcomes Collaboration (PCOC) is a consortium of four universities. PCOC supports the consistent comparison and measurement of the quality of service outcomes and offers benchmarking opportunities and the capacity to monitor changes in clinical outcomes and activity. PCOC is a voluntary quality program that uses standardised validated clinical assessment tools to benchmark and measure outcomes in palliative care.

⁶¹ DOHA, *National Palliative Care Strategy 2010*

- the Palliative Care Research Program, managed by the National Health and Medical Research Council, which aims to improve the quality of palliative care, inform policy development, improve clinical practice and develop researcher capacity.
- the Palliative Care Knowledge Network (CareSearch), a web-based one stop shop of information and practical resources for clinicians, other health care professionals providing palliative care, researchers, patients and carers.
- involvement by the Australian Institute of Health and Welfare in the development, annual data collection and reporting on high-level performance indicators for national and local palliative care activities.⁶²

1.7.5 Quality improvement

The Australian Government also funds support for quality improvement for palliative care services. Palliative Care Australia is funded to manage the National Standards Assessment Program (NSAP), a national framework for continuous quality improvement. The NSAP builds on the Palliative Care Australia Standards for providing quality palliative care and includes a process for review of service quality.⁶³ The program supplies palliative care service providers with the tools and resources for self-assessment against the national standards. It also develops resources that will support and enhance the ability of services to improve the quality of care within their existing quality improvement processes and accreditation cycles.

⁶² DOHA, *ibid.*

⁶³ Palliative Care Australia (PCA), *The National Standards*, accessed 15 February 2013 from <http://www.palliativecare.org.au/Standards/TheNationalStandards.aspx>; and Victorian Department of Health, *Frequently Asked Questions – Palliative Care Service Delivery Framework*, accessed 15 February 2013 from <http://www.health.vic.gov.au/palliativecare/documents/sdffmr-faq.pdf>

Chapter 2. Community care

2.1 Home and Community Care Program

Before July 2012, the Home and Community Care (HACC) Program was a joint program and funding responsibility of the Australian and state and territory governments. HACC services supported people over 65 and younger people with a disability and carers to be more independent at home and in the community. Until July 2012, the HACC program provided funding to deliver services in the home and in community settings to eligible people of all ages.

Since July 2012, the Queensland Government has been solely responsible for community care services for people aged under 65 (under 50 if they are Aboriginal or Torres Strait Islander) and the Australian Government responsibility is for HACC services for people aged 65 and over (or 50 and over).

The transition of roles and responsibilities were agreed between the Australian Government and six of the state and territory governments in the *National Partnership Agreement on Transitioning Responsibilities for Aged Care and Disability Services*.⁶⁴ Victoria and Western Australia continue under the current HACC program as they are not signatories to the transition of responsibilities.

Part 7 of this report discusses the committee's consideration of the segmenting of HACC services according to age of the client and needs, as required by the terms of reference.

2.2 Living Longer Living Better – aged care

In April 2012 the Australian Government announced proposed aged care reforms, *Living Longer Living Better*. It intends to pursue a ten year plan to improve the aged care system with a staged approach to reform and funding for new initiatives to build a fairer, more sustainable and nationally consistent aged care system. The reforms will address challenges facing the aged care system, including financial and capital pressures, lack of access to information and workforce needs. The reforms recognise that older Australians want to stay in their homes for as long as possible.⁶⁵

The Australian Government's reforms aim to incorporate 'consumer directed care' into the planning and management of care. This approach allows consumers and carers greater "power to influence the design and delivery of the services they receive"⁶⁶ including where services will be received, the timing and scheduling of services, and how care is to be shared between informal and formal carers. Consumer directed care principles will be embedded into home care packages and piloted in residential care settings as part of the reforms.⁶⁷

New Commonwealth infrastructure for aged care aims to support better co-ordination of services, information and assistance for consumers. The creation of a single gateway or 'principal entry point' to the aged care system, in particular, should make it easier for timely and reliable information to be accessed by older people about care and its financing.⁶⁸ An Aged Care Workforce Productivity Strategy, with a Workforce Compact to be developed between providers, unions and consumer groups, will seek to strengthen the aged care workforce.

The reforms seek to improve links between the aged care and health systems and committed additional funding for better palliative care and palliative care training in aged care settings and

⁶⁴ COAG, *National Partnership Agreement on Transitioning Responsibilities for Aged Care and Disability Services*, 2008, available at http://www.federalfinancialrelations.gov.au/content/npa/health_reform/transitioning_responsibilities/national_partnership.pdf

⁶⁵ DOHA, *Living Longer. Living Better. Aged Care Reform Package*, 2012, Canberra, available at [http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA2578620005D57ACA2579E2007B9DFC/\\$File/D0769%20Living%20Longer%20Living%20Better%20SCREEN%20070512.pdf](http://www.health.gov.au/internet/publications/publishing.nsf/Content/CA2578620005D57ACA2579E2007B9DFC/$File/D0769%20Living%20Longer%20Living%20Better%20SCREEN%20070512.pdf)

⁶⁶ DOHA, *ibid.*, p.42

⁶⁷ DOHA, *ibid.*, p.42

⁶⁸ DOHA, *ibid.*, p.85

projects with a focus on preventing hospitalisation of older Australians and improving access to complex health care services.

2.3 National Disability Insurance Scheme

In early 2010, the Australian Government asked the Productivity Commission to undertake an inquiry into a National Disability Long-term Care and Support Scheme and assess the costs, cost effectiveness, benefits and feasibility of an approach to funding people with a disability for long-term essential care and support on an entitlement basis.⁶⁹ The Commission reported in 2011, finding that the “existing disability support ‘system’ is unsustainable on multiple grounds”. The report recommended a National Disability Insurance Scheme (NDIS), to be overseen by a national agency, which would provide assessments and funding to individuals and organisations, noting that the benefits of a NDIS from an economic perspective would exceed the costs.⁷⁰ The scheme would be delivered through the use of an insurance approach, like Medicare. The Commission also recommended a second, smaller National Injury Insurance Scheme to address catastrophic injuries from accidents. This would have the same goals as the NDIS, but would be funded differently and would draw on existing arrangements in some states and territories.⁷¹

The Australian Government supported the Productivity Commission’s recommendations for change. In August 2011, the Council of Australian Governments (COAG) agreed on the need for major reforms to disability services, noting that disability services are currently the responsibility of state and territory governments and recognising that reform would require shared and coordinated effort. Foundational reforms include development of a national assessment framework, nationally consistent service and quality standards for the disability services sector and a comprehensive national disability services workforce strategy.⁷²

The National Disability Agreement (NDA) and the National Disability Strategy 2010–2020, agreed by all governments, underpin the implementation of the reforms to disability services. Under the agreement, governments agreed to reform their services, including:

- the improvement of provision of services and opportunities to enhance the capacity of people with a disability
- ensuring that services are person-centred and providing timely access to the necessary support needs
- identifying, planning and responding to the development and support needs of people with a disability at an early stage and at key life transition points, and
- supporting the role of carers and families, including strengthening their informal support networks.⁷³

The NDA was revised in July 2012 to include five new reform priority areas and improvements to the performance framework. The agreement also reflected the changed responsibilities for aged and disability care and COAG’s commitment to commence foundation work for a NDIS.⁷⁴ New priorities for governments under the agreement are to:

⁶⁹ Productivity Commission, *Disability Care and Support, Report no. 54, Overview and Recommendations*, 2011, Canberra, p.iv, available at http://www.pc.gov.au/_data/assets/pdf_file/0014/111272/disability-support-overview-booklet.pdf

⁷⁰ Productivity Commission, *ibid.*, p.7

⁷¹ Productivity Commission, *ibid.*, p.10 and executive summary, p.5

⁷² COAG, COAG communiqué, *Productivity Commission Report on Disability Care and Support*, 19 August 2011, accessed 5 February 2013 from [http://www.coag.gov.au/node/76#Productivity Commission Report on Disability Care and Support](http://www.coag.gov.au/node/76#Productivity%20Commission%20Report%20on%20Disability%20Care%20and%20Support)

⁷³ Standing Council on Federal Financial Relations, *National Agreements*, accessed 3 February 2013 from http://www.federalfinancialrelations.gov.au/content/national_agreements.aspx

⁷⁴ Disability Policy & Research Working Group, *Revised National Disability Agreement*, accessed 5 February 2013 from <http://www.dprwg.gov.au/national-disability-agreement>

- build the evidence base for disability policies and strategies and provide a stronger basis for future policy decisions
- enhance family and carer capacity through strategies that focus on improving outcomes for carers
- pursue individual and/or self-directed funding arrangements for disability services that emphasise choice and control by the person with disability through strategies for increased choice, control and self-directed decision-making
- maintain innovative and flexible support models for people with high and complex needs
- develop employment opportunities for people with a disability through models for enhancing independence and work readiness at different life transition points.⁷⁵

The National Disability Strategy 2010–2020 sets out a ten year national policy framework and commits all levels of government to a unified, national approach to policy and program development.⁷⁶

High-level principles for a NDIS were agreed by COAG in April 2012. A transition agency for the NDIS commenced work on co-ordination of the detailed design work for a launch of the scheme in July 2012, and launch sites in New South Wales, Victoria, South Australia, Tasmania and the Australian Capital Territory were agreed to. An Intergovernmental Agreement on the National Disability Insurance Scheme Launch was signed on 7 December 2012. Legislation to establish the framework of the NDIS (including the design, funding and governance) and to establish the National Disability Insurance Scheme Launch Transition Agency was passed in March 2013. The first stage of the NDIS, now to be called 'Disability Care Australia' will commence in mid-2013.⁷⁷

2.4 Queensland Your Life Your Choice

In September 2012, the Queensland Government announced a trial of self-directed funding for disability support and services, *Your Life Your Choice*.

Self-directed support is a funding approach that enables people with a disability and their families to have greater choice and control over the disability services they receive. People with a disability can choose between services that are delivered through non-government service providers as at present, or choose to direct the support themselves using funding and resources to plan, purchase and select support that best suits their needs. *Your Life Your Choice* provides the framework for how self-directed support operates in Queensland.⁷⁸

Your Life Your Choice is being established in two phases. The first phase – a host provider model – was in place by the end of 2012. Under the model, endorsed providers assist people with a disability to purchase services and organise supports. The second phase, planned for 2013, will introduce direct funding to a person with a disability as well as expand the host provider model.⁷⁹

⁷⁵ Disability Policy & Research Working Group, *National Reform Priorities*, accessed 6 February 2013 from <http://www.dprwg.gov.au/national-disability-agreement/previous-national-reform-priorities>

⁷⁶ Department of Families, Housing, Community Services and Indigenous Affairs (FAHCSIA), *National Disability Strategy*, accessed 5 February 2013 from <http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-strategy>

⁷⁷ Minister for Families, Community Services and Indigenous Affairs, *Progress towards a National Disability Insurance Scheme*, Statement, 11 September 2012, accessed 6 February 2013 from <http://jennymacklin.fahcsia.gov.au/node/2088>

⁷⁸ Department of Communities, Child Safety and Disability Services (DCCSDS), *Your Life Your Choice*, accessed 6 February 2013 from <http://www.communities.qld.gov.au/disability/key-projects/your-life-your-choice>

⁷⁹ Health and Community Services Committee, *Disability Services (Your Life Your Choice) Amendment Bill 2012*, Report No. 10, 2012, Brisbane, p.2, available at [http://www.parliament.qld.gov.au/documents/committees/HSCS/2012/DisabServLYCAdmtBill2012/RptDS\(YLYC\)AdmtB2012.pdf](http://www.parliament.qld.gov.au/documents/committees/HSCS/2012/DisabServLYCAdmtBill2012/RptDS(YLYC)AdmtB2012.pdf)

The *Your Life Your Choice* framework is expected to enable people with a disability, their families and support networks, service providers and the wider community to design, develop and extend their personalised model of self-directed support in preparation for the NDIS.⁸⁰

The Disability Services (Your Life Your Choice) Amendment Bill 2012, which was passed by the Queensland Parliament in October 2012, amended the *Disability Services Act 2006* to provide the Minister for Communities, Child Safety and Disability Services the power to direct funding to an individual. The explanatory notes to the Bill noted that the change enabled by the amendments would align Queensland with other states and territories and “ensure that Queensland is well positioned to transition to any future NDIS”.⁸¹

On 12 December 2012, the Premier announced that Queensland would commit to implementing the NDIS.⁸² On 8 May 2013, as the committee was finalising this report, the Premier announced that Queensland had reached an agreement with the Commonwealth for full implementation of the NDIS in Queensland.⁸³

⁸⁰ DCCSDS, *Your Life Your Choice Self-directed Support Framework*, Brisbane, p.3, available at <http://www.communities.qld.gov.au/resources/disability/key-projects/your-life-your-choice/ylc-self-directed-support-framework.pdf>

⁸¹ Queensland Government, Explanatory Notes, Disability Services (Your Life Your Choice) Amendment Bill 2012, p.2, available at <http://www.legislation.qld.gov.au/Bills/54PDF/2012/DisabServAB12E.pdf>

⁸² Hon. Campbell Newman, Premier, *Queensland Plans on NDIS*, Joint ministerial statement, 12 December 2012, accessed 8 February 2013 from <http://statements.qld.gov.au/Statement/2012/12/12/queensland-government-plan-on-ndis>

⁸³ Hon. Campbell Newman, Premier, *Queensland commits to full NDIS*, Joint ministerial statement, 8 May 2013, accessed 9 May 2013 from <http://statements.qld.gov.au/Statement/2013/5/8/queensland-commits-to-full-ndis>

Chapter 3. Carers policy and services for carers

3.1 The importance of carers

Carers are an integral part of the provision of palliative care and home care. Carers are “people who provide personal care, support and assistance to people with a disability, medical condition (including terminal and chronic illness), mental illness or frailty due to age”.⁸⁴

A significant proportion of caring in Australia is unpaid and ‘informal’. Unpaid carers make a large contribution to the work of caring but also face a number of challenges in their participation in economic, social and community life. While some steps have been taken to address better support for carers, most recently the Australian Human Rights Commission has drawn attention to the impact of unpaid caring responsibilities on workforce participation and retirement incomes and savings in its report *Investing in care: Recognising and valuing those who care*.⁸⁵

The need for recognition of the role of carers, and the need to better support carers, has been acknowledged over a number of years by the Australian and state and territory governments. The release of *Who Cares ...?: Report on the inquiry into better support for carers*⁸⁶ by the House of Representatives Standing Committee on Family, Community, Housing and Youth in April 2009 highlighted the lack of recognition of the carer role, the financial stresses and physical, emotional and social impacts of caring and the difficulty of accessing information and assistance from complex and inflexible community care systems. It also noted the lack of choice for carers in terms of participation in the workforce due to shortages of respite care and inflexible employment practices.

Who Cares ...? recommended that the Australian Government and each state and territory review existing legislation and policy to ensure that carers were adequately recognised. It also recommended the development of a nationally consistent carer recognition framework encompassing legislation and a national strategy to build on and complement state and territory carer policies.

3.2 Recognition for carers in Queensland

The *Queensland Carers (Recognition) Act 2008* (the Carers Act) recognises the important contribution made by carers for people with a disability, people who are chronically ill and people who are frail.

The Carers Act provides for the interests of carers to be considered in decisions about the provision of services that impact on carers. It also requires public authorities to recognise and support carers through services. The Carers Act also established the Queensland Carers Advisory Council and the *Queensland Carers Charter*. The Office of Carers (part of the Department of Communities, Child Safety and Disability Services) has responsibility for carer policy and programs in Queensland. It is the main government contact point for carers’ issues and provides secretariat support to the Queensland Carers Advisory Council.

The Queensland Carers Advisory Council advises the Minister for Communities, Child Safety and Disability Services on matters relating to carers and works to advance carers’ interests. The Council has 12 members, including four carers, one of whom must be a grandparent carer.

⁸⁴ DOHA, *National Respite for Carers Program – Respite Service Providers’ Program Manual*, 2012, Canberra, p.9, available at [http://www.health.gov.au/internet/main/publishing.nsf/content/F5A31D4CDBF8EBE7CA256F19000F476C/\\$File/NRCP_July2012%20FINAL.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/F5A31D4CDBF8EBE7CA256F19000F476C/$File/NRCP_July2012%20FINAL.pdf)

⁸⁵ Australian Human Rights Commission, *Valuing Unpaid Care Work in Australia Research Project*, accessed 24 April 2013 from http://humanrights.gov.au/sex_discrimination/VUCW_australiaResearchPrj/index.htm

⁸⁶ Parliament of Australia, House Standing Committee on Family, Community, Housing and Youth, *Inquiry into better support for carers*, accessed 24 April 2013 from http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=fchy/carers/report.htm

The *Queensland Carers Charter* has 13 principles to ensure that the significant contribution carers make to the community is recognised. The principles include that the views and needs of carers must be taken into account in policy decisions and in the assessment, planning, delivery and review of services affecting carers. Under the Carers Act, public authorities must ensure the authority and its officers and employees have an awareness and understanding of the *Carers Charter* and take action to reflect the principles of the Charter in providing any services that affect carers and the persons they care for.

The Queensland Carer Action Plan 2011–2014 is another important component of the framework for support for carers in Queensland. The plan was developed in consultation with the Queensland Carers Advisory Council and key community representatives and is based on three priority areas for carers: recognition and respect, support, and participation. It builds on the previous Carer Action Plan 2006-10. The priority areas in the Queensland Carer Action Plan 2011-14 align with the National Carer Strategy.

3.3 The National Carer Recognition Framework

At the Commonwealth level, the National Carer Recognition Framework includes the *Carer Recognition Act 2010* (Cwlth) (the Carer Recognition Act) and the National Carer Strategy. Development of the framework was part of the Australian Government's response to the recommendations of *Who Cares ...?*. The Carer Recognition Act recognises the significant role of carers and the importance of ensuring that the needs of carers are considered in the development, implementation and evaluation of policies, programs and services.

The National Carer Strategy was developed by the Australian Government in consultation with carers, state and territory governments, service providers and peak organisations. The strategy includes six important priority areas for national action – recognition and respect, information and access, economic security, services for carers, education and training and health and wellbeing.

The strategy reflects the principles of the Carer Recognition Act. It complements state and territory government strategies, policies and plans to support carers and reforms occurring, or being considered across the aged care, disability, mental health, primary health care, hospital and community care systems. Action and implementation plans set out practical actions to be taken against each of the strategy's priority areas, to ensure that reforms consider and support the role of carers.

3.4 Respite for carers

Australian Government funding for carer respite is provided under the National Respite for Carers Program (NRCP). Carers and foster carers of younger people (under the age of 65 years, or under 50 if Aboriginal or Torres Strait Islander) with disabilities are eligible for some respite services. However, the NRCP-funded Employed Carer and Overnight Community Respite initiatives are specifically targeted to people aged 65 and older. Carers of younger people with disabilities are not included in the NRCP, with the exception of carers of people with early onset dementia. Respite care for children with disabilities is a Queensland government responsibility.

Under the aged care reforms addressed in *Living Longer, Living Better*, the NRCP is to be expanded and incorporated into the Australian Government Home Support program to be introduced from 1 July 2015. The Home Support program is intended to bring together all of the services currently providing basic home support – including the Australian Government HACC program, the NRCP, the Day Therapy Centres program and the Assistance with Care and Housing for the Aged Program. Respite services will also be made more flexible to better support greater choice and control by recipients. Currently respite care packages are limited and do not meet demand.

Carers of people in Queensland who are eligible for specialist disability services may be able to access respite support through a Queensland Disability Service Centre. Otherwise, carers of people with a disability or condition that restricts their day-to-day living who are under 65 (or under 50) may be

eligible to access in-home or centre-based respite and counselling support through the Queensland Community Care program. *Part 2* describes current services.

3.5 Australian Government support for carers

3.5.1 Income support

As part of its income support arrangements, the Australian Government provides the Carer Payment and Carer Allowance to eligible carers. The Carer payment is an income support payment for people whose caring responsibilities prevent them from undertaking substantial paid employment. The Carer Allowance is an income supplement for people who provide daily care and attention at home to a person with disability or a severe medical condition.

3.5.2 Other Australian Government support for carers

The National Carer Counselling Service and bereavement services are also provided by the Australian Government under the National Carers Recognition Framework. Increased counselling services will be provided as part of the aged care reforms.

An existing network of 52 Commonwealth Respite and Carelink Centres, run by non-government organisations that provide HACC services, provide a single point of contact for the public, service providers, general practitioners and other health professionals for information on community, aged and disability services and carer support. They can also help to arrange respite care. As part of the aged care reforms, the Australian Government plans to establish a regional network of carer support centres from July 2014. The new regional Carer Support Centres will broker emergency respite, information and support, education and counselling, and referral for other services where appropriate.

3.6 Other Queensland government support for carers

Queensland provides carers with practical assistance. The Carer Business Discount Card is a concession card that provides eligible carers with discounts on goods and services from participating businesses. The Companion Card provides for people with a disability to obtain a companion ticket from businesses, organisations, venues or activities which have formally registered with the program when significant assistance is to attend activities and venues. These schemes are partnerships between the Queensland Government and Queensland businesses.

The Queensland Government also provides a website, Disability Online, to help people with a disability, their carers, friends and family, to access information about services that support carers.⁸⁷

⁸⁷ Accessed 1 March 2013 from www.communities.qld.gov.au/disability/

Part 2 Current services in Queensland

Chapter 4. Palliative care services

4.1 Introduction

The committee's terms of reference require it to consider the capacity and future needs for palliative care and home and community care services in Queensland, and the adequacy, effectiveness and efficiency of services. This part of the report provides an overview of current services in Queensland. It is intended to provide a starting point for consideration of the evidence presented to the committee about future needs, and the capacity, adequacy, effectiveness and efficiency of services, which are discussed in later chapters of this report.

Part 1 of this report summarised the roles of the Commonwealth and the State in funding and policy setting for palliative care and home care services. Broadly, palliative care is funded by both the Australian and Queensland Governments, contributions from individuals, and fundraising by non-government organisations. Since mid-2012, the Australian Government has had funding and policy responsibility for home and community care for people aged 65 and over (or 50 and over for Aboriginal or Torres Strait Islander people), and the Queensland government has funding and policy responsibility for home and community care for people aged under 65. The potential impact of this separation of responsibilities is discussed in Part 7.

4.1.1 What is palliative care?

Palliative care affirms life and regards dying as a normal process, and intends neither to hasten nor postpone death. It is defined by the World Health Organization (WHO) as:

... an approach that improves the quality of life of patients and their families facing the problems 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.

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 patients 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, and
- 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 complication.

In addition, the WHO states that palliative care for children:

... is the active total care of the child's body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress.

Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes.⁸⁸

4.1.2 Settings for palliative care services

Palliative care services are provided in a variety of settings – including public and private hospitals, hospices, residential aged care facilities, and in a person's home – through “a complex service network of providers with multiple funding sources”.⁸⁹ Services are provided by specialist palliative physicians, other medical specialists such as oncologists, general practitioners, nurse practitioners,

⁸⁸ World Health Organization (WHO), *WHO Definition of Palliative Care*, accessed 8 January 2013 from <http://www.who.int/cancer/palliative/definition/en/>

⁸⁹ Queensland Health, Submission no. 35, p.3

nurses, allied health professionals, counsellors, pastoral carers and volunteers. A significant proportion of palliative care is provided by carers who are family members or significant others. Services may be delivered by a Hospital and Health Service, a private hospital, a non-government organisation providing home nursing and other care services, allied health professionals, or a non-government hospice.

Later chapters of this report consider the capacity of palliative care services, including the workforce needed to meet future needs and the services needed to meet the needs of carers.

4.2 Hospital and Health Services

Queensland Health, through Hospital and Health Services (HHSs), provides palliative care services for people in their homes and as hospital inpatients. Some public hospitals have a designated specialist inpatient palliative care unit, others have a designated palliative care program which functions in more than one part of the hospital. Most palliative care is delivered outside of the specialist palliative care services, with people being supported by generalist palliative care services (Level 1) in the community, across a range of health settings (Level 2 to Level 4 palliative care services),⁹⁰ and in the community, cared for by private practitioners.

In 2010–11 public acute hospitals provided 6 599 admitted patient episodes of care and 10,887 non-admitted patient occasions of service (see glossary for definitions).⁹¹ In 2010–11 there were 56,683 bed days of palliative care; which included palliative care in a designated palliative care unit, in a designated palliative care program or where the clinical intent of care was palliative.⁹²

The most specialised public sector palliative care services have medical specialists with credentials in palliative medicine and access to other highly specialised services such as pain management. Other public sector palliative care services range from business hours services for palliative patients who are at home, to inpatient care palliative care services.

4.2.1 Clinical Services Capability Framework

Table 1 below lists the various levels of palliative care service in public sector health services. The six service levels are described in the Queensland Health Clinical Services Capability Framework (CSCF) according to complexity and intensity. The CSCF outlines minimum requirements for health services in Queensland public and licensed private health facilities, including minimum service, workforce and support service requirements for each level of service.⁹³ Chief executives of HHSs are responsible for implementation of the CSCF in the public sector.⁹⁴

A summary of key features of each of the six service levels is below, particularly the services provided (or accessible) and the workforce requirements. The CSCF recognises that services are part of a complex network of public and private service providers, and that access to parts of that network are important, as highly specialised services are not available in all locations. As the CSCF is detailed, the summary below cannot reflect all information in the CSCF, which should be referred to for more complete details.

The CSCF states that palliative care is delivered through a network of specialist and primary care providers, that it should be based on quality management principles that comply with the *Standards*

⁹⁰ Queensland Health, *ibid.*, p.7

⁹¹ Queensland Health, *ibid.*, p.4

⁹² Queensland Health, *ibid.*, p.5

⁹³ Queensland Health, *Clinical Services Capability Framework for Public and Licensed Private Health Facilities, v3.1*, accessed 23 February 2013 from <http://www.health.qld.gov.au/cscf/>

⁹⁴ Queensland Health, *ibid.*,

*for Providing Quality Palliative Care for all Australians,*⁹⁵ and be responsive to differences in culture, location, age, health, and impairment status.⁹⁶

Examples of level 5 and level 6 palliative care services in two locations are provided on page 8.

4.2.2 Geographical location of public sector palliative care services

Palliative care services are located in all HHSs; however, in some areas, only low-complexity Level 1 or Level 2 services are available. The two highest level specialist services (Level 5 and Level 6) are located in south-east Queensland and Townsville. Their location highlights the importance of those services providing consultation and liaison support to less specialised services, other public sector hospitals, and to general practitioners (GPs) and RACFs, including health services located outside of the area. A map of the HHS areas and palliative care services is on page 6.

⁹⁵ The standards, prepared by Palliative Care Australia, are available at <http://www.palliativecare.org.au/Default.aspx?tabid=2051>

⁹⁶ Queensland Health, *ibid.*, pp.1–3

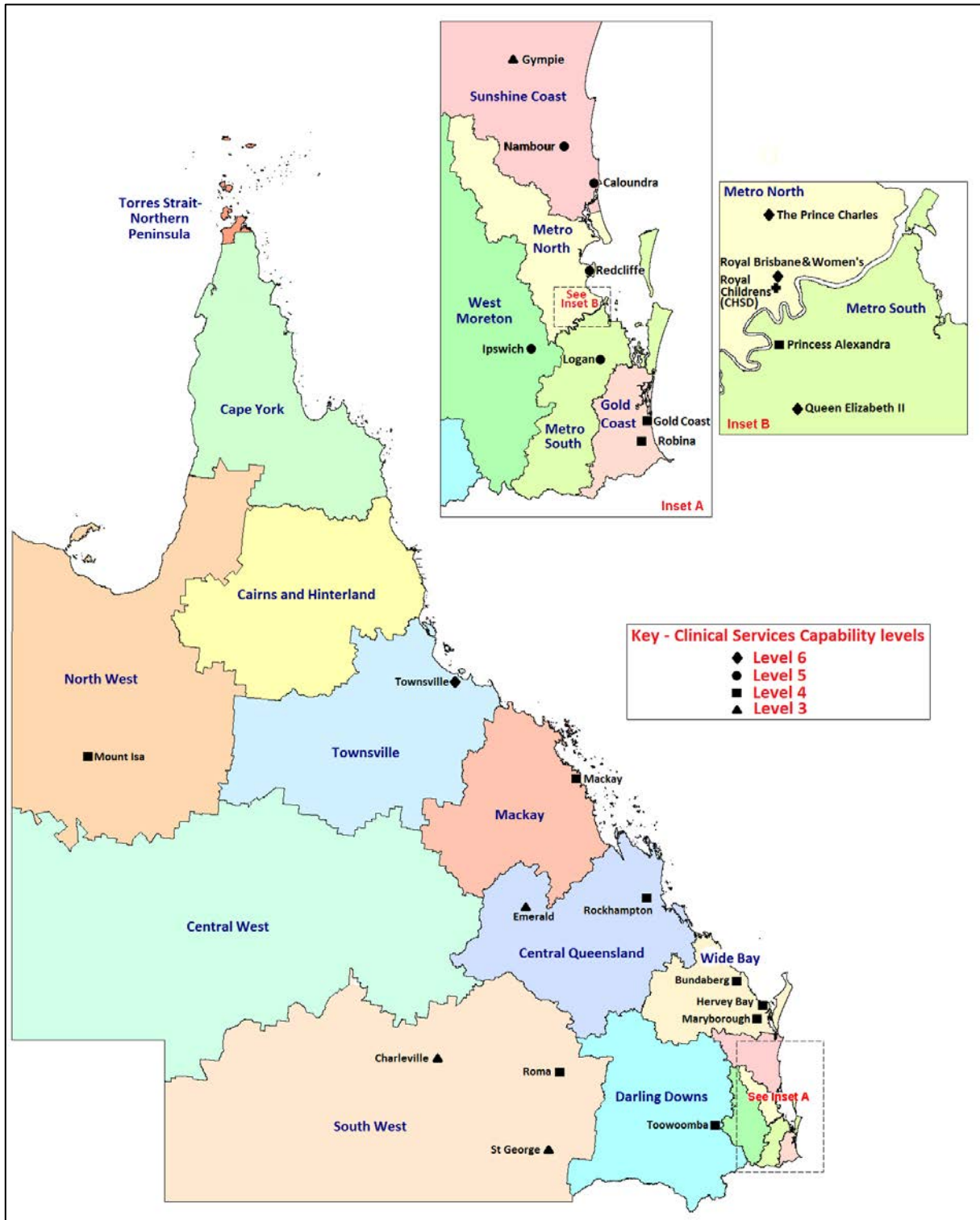
Table 1: Summary of palliative care service levels in the Clinical Services Capability Framework

Service level*	Key features, particularly the services provided (or accessible) and the workforce requirements
Level 1	Provides low complexity care (primarily nursing and allied health) during business hours in the home or an ambulatory setting. Medical services may be through a general practitioner. Workforce requirements are at least one registered nurse; allied health professionals may be accessible (e.g. by telehealth). There is 24-hour access to specialist palliative care consultancy, access to bereavement support, access to equipment hire services, and access to subcutaneous infusion devices for symptom management.
Level 2	Provides community based care, and has access to inpatient beds if 24-hour nursing care is required. It has 24-hour access to telehealth and a higher level palliative care service for advice. It also has access to NGO support services (e.g. domiciliary nursing). Workforce requirements are as for Level 1, plus access to a medical specialist with credentials in palliative medicine, and access to a medical practitioner to review patients.
Level 3	Identified as a palliative care service, it provides a continuum of care between community and acute inpatient settings. Community outreach and inpatient services may be provided by the service, or it may collaborate with other service providers for those services. A regular on-site palliative care clinic and specialist community or inpatient palliative care may be accessible. Workforce requirements in addition to level 2 are: 24-hour access to a medical practitioner with credentials in palliative medicine (possibly off-site); a nurse manager available to oversee patient care; and a registered nurse/s. Medication is on-site; there is access to pastoral/spiritual care staff and a skilled bereavement counsellor and access to interpreters and/or cultural advocates for Aboriginal and Torres Strait Islander patients and those from other cultural backgrounds.
Level 4	Provides ambulatory and/or inpatient care for patients with moderately complex symptom management needs; this may be as the major care provider for patients at home or by providing input and support to the primary providers of home care. Services may include home visiting by nursing and/or allied health staff under a service agreement with another provider. Inpatient services may include designated palliative care beds. Services are coordinated by a health professional with skills and experience in palliative care. There is close liaison with the Emergency Department (where available) and access to mental health services. Workforce requirements include; on-site 24-hour access to medical practitioners; 24-hour access to a medical specialist with credentials in palliative medicine; a registered nurse in charge of each shift; and access to an on-site multidisciplinary team including a pharmacist and allied health professionals.
Level 5	Able to manage clinically and psychosocially complex issues, it has allocated palliative care inpatient beds, which may be in a dedicated unit. It provides, or is part of a network that provides, off-site services with a medical practitioner available 24 hours a day. In addition to Level 4 services, it provides complex symptom management (including access to invasive procedures), procedural medicine, on-site bereavement service, access to consultation psychiatry services, and access to interventional pain management. Workforce requirements, in addition to those of a Level 4 service are: a medical specialist with credentials in palliative medicine available 24-hours; a palliative care nurse manager coordinating care; a registered nurse with palliative care qualifications or competency in palliative care available 24-hours; a nurse practitioner with advanced training (desirable); a multidisciplinary palliative care allied health team; a dedicated bereavement counsellor and access to discharge coordinators.
Level 6	Provides a palliative care unit with capacity to manage the highest level of patient risk or complexity, and can provide highly complex symptom management. The service is linked to Level 5 or Level 6 services from other specialties. After hours services about complex symptom management are provided for other services; interventional pain management is readily available or available for review within 48 to 72 hours; and there is access to invasive procedures for high-risk patients. In addition to the workforce requirements for level 5, postgraduate palliative care qualifications are recommended for nursing and allied health professionals, the lead medical practitioner is a specialist with credentials in palliative medicine; there is a specialist palliative care pharmacist, and palliative care nurse practitioners with relevant advanced training.

* Each level of palliative care service should have the services and workforce of the lower level services, plus those summarised for each level. The model of palliative care services provided varies between locations.

Source: Queensland Health, *Clinical Services Capability Framework for Public and Licensed Private Health Facilities*, v3.1, accessed 23 January 2013 from <http://www.health.qld.gov.au/cscf/>

Map 1: Location of Hospital and Health Service Levels 3 to 6 Palliative Care Services



Source: Information in this map is sourced from a summary of palliative care clinical services capability self-assessed levels provided by Queensland Health on 22 February 2013; Queensland Health, *Service Agreements*, accessed 25 February 2013 from http://www.health.qld.gov.au/hhsserviceagreement/html/service_agreements.asp, and Queensland Health, *Health Service Districts by Queensland Health Facilities*, available at http://www.health.qld.gov.au/services/images/HSD11_Hosps.jpg.

Table 2: Location and number of Hospital and Health Service palliative care services by Clinical Services Capability Framework level

Hospital and Health Service	Level 6 ⁹⁷	Level 5	Level 4	Level 3	No. Level 2 services	No. Level 1 services
Cairns and Hinterland					4	13
Cape York					2	10
Central Queensland			Rockhampton Hospital	Emerald Hospital	3	2
Central West					4	8
Children's Health Queensland	Royal Children's Hospital					
Darling Downs			Toowoomba Hospital		5	13
Gold Coast			Gold Coast Hospital Robina Hospital			
Mackay			Mackay Hospital		3	4
Metro North	The Prince Charles Hospital	Redcliffe Hospital	Royal Brisbane and Women's Hospital			1
Metro South	QEIJ Jubilee Hospital	Logan Hospital Princess Alexandra Hospital			1	
North West			Mount Isa Hospital		5	
South West			Roma Hospital	Charleville Hospital St George Hospital	8	3
Sunshine Coast		Caloundra Hospital Nambour Hospital		Gympie Hospital		
Torres Strait and Northern Peninsula					1	
Townsville	Townsville Hospital				1	3
West Moreton		Ipswich Hospital			4	
Wide Bay			Bundaberg Hospital Hervey Bay Hospital Maryborough Hospital			8
Source: Information in this table is sourced from a summary of palliative care clinical services capability self-assessed levels provided by Queensland Health on 22 February 2013, and from Queensland Health, <i>Service Agreements</i>						

⁹⁷ See Table 1 on page 22 for a summary of each service level for palliative care services in the Queensland Health *Clinical Services Capability Framework* ver 3.1

Example 1: Examples of models of care in HHS palliative care services

Townsville Palliative Care Centre – Level 6

The purpose built Townsville Palliative Care Centre opened in 2009 on the Townsville Hospital campus. It has 15 inpatient beds (with future capacity for 20), offices for outreach services and research and educational facilities.

The Centre is a Level 6 specialist palliative care service. It provides: inpatient care; outpatient clinics; consultation services to Townsville Hospital and primary care providers in the region; outreach services to patients in the community; counselling and support for patients, relatives and staff, and educational programs. The Centre has contracted Blue Care to provide domiciliary nursing services to patients who remain at home.

The multidisciplinary team at the Centre consists of the Director of Palliative Care, consultant, inpatient registrar, community registrar, senior medical officer, occupational therapist, physiotherapist, dietician, speech therapist, pharmacist, Indigenous liaison officer, coordinator of volunteers, social workers, volunteers and nursing staff.

Ipswich Hospital Palliative Care Service – Level 5

Ipswich Hospital has a Level 5 palliative care service. The palliative care service currently has 10 inpatient beds (with a further 3 beds to open by 2014 and provides outpatient and outreach services.

The hospital hosts monthly district Palliative Care Interagency meetings which are chaired by the Palliative Care Consultant. The management, prognosis, progress and care of every palliative care patient in the community are discussed at the meeting. This includes those patients in rural districts, receiving domiciliary services and outreach services, public and private inpatients, outpatients, and those in the Ipswich Hospice.⁹⁸

4.3 Non-government organisations

Non-government organisations (NGOs) are significant providers of home care services, both in palliative care and through the Queensland Community Care Services (see Chapter 5 below). Many also provide services under the Australian Government Home and Community Care (HACC) program for people aged 65 and over (or 50 and over if Aboriginal or Torres Strait Islander).

Generally NGOs receive funding under contracts with a HHS (to provide palliative care), and/or the Department of Communities, Child Safety and Disability Services (to provide community care) and/or the Australian Government (to provide HACC services). In addition, Hospital and Health Services purchase services (called 'scripting' of services) from NGOs for individual patients.⁹⁹

Non-government hospices are described in section 4.5.

⁹⁸ Ipswich Hospice Care Inc., Submission no. 59, p.23

⁹⁹ Queensland Health, Submission no. 35, p.5

Example 2: NGO provider of palliative care and home care**Blue Care**

Blue Care is a large not-for-profit provider of community health and residential care services. Blue Care employs over 8,000 staff in Queensland and northern New South Wales.

Blue Care's palliative care services include home nursing, allied health services, pain and symptom management, advice on equipment for nursing care at home, advice on financial assistance and practical help, assistance and relief for the care-giver (in-home respite care), liaison between home, hospital and doctors, and emotional and bereavement support.

Blue Care is contracted by the West Moreton Hospital and Health Service to provide domiciliary nursing services to palliative care patients. Blue Care works closely with the Palliative Care Centre at Townsville to ensure patients' needs are met when they are discharged from hospital.

Blue Care also provides community health and home care for clients who need support at home because of their disability or frailty, but may not need palliative care.

4.4 Private hospital palliative care services

Private hospitals and private day hospitals in Queensland are licensed under the *Private Health Facilities Act 1999*. Twenty six facilities in Queensland are licensed to provide palliative care services in 228 beds. A majority of the licensed palliative care beds provide palliative care services "at a more generalist level (Levels 2 to 4)" in the CSCF.¹⁰⁰ Private hospitals provided a 26,845 bed days in 2010–11.¹⁰¹ The private hospital palliative care services "may be provided in a range of ward settings, including general medicine and oncology, and not all licensed beds are used solely for the purpose of palliative care".¹⁰²

Private hospital providers of palliative care include St Vincent's Brisbane (Tarmons Centre) at Kangaroo Point, which provides inpatient palliative care, outpatient and home care,¹⁰³ Wesley Hospital, which provides inpatient and outpatient palliative care,¹⁰⁴ and Canossa Private Hospital at Oxley which provides palliative care including symptom management, end of life care and crisis care.¹⁰⁵

4.5 Hospices**4.5.1 Overview**

Queensland has a small number of hospices. Some provide inpatient care, others provide specialist palliative care in a person's home, and some provide a combination of inpatient and home-based palliative care.

¹⁰⁰ Queensland Health, *ibid.*, p.7

¹⁰¹ Queensland Health, *ibid.*, p.5

¹⁰² Queensland Health, *ibid.*, p.7

¹⁰³ St Vincent's Hospital Brisbane, *The Tarmons Centre*, accessed 21 February 2013 from <http://www.stvincentsbrisbane.org.au/our-services/tarmons-centre.html>

¹⁰⁴ Blue Care and UnitingCare Health, Submission no. 24, pp.13–21

¹⁰⁵ Canossa Private Hospital, *Palliative Care*, accessed 21 February 2013 from <http://www.canossa.org.au/page.php.43.html>

4.5.2 Hospices with inpatient beds

Three non-government hospices are licensed under the *Private Health Facilities Act 1999* to provide inpatient care; they are Hopewell Hospice on the Gold Coast, Ipswich Hospice and Toowoomba Hospice.¹⁰⁶

- **Hopewell Hospice** has eight inpatient beds, and provides inpatient and home-based palliative care as well as respite care for Gold Coast residents. Inpatient services are predominantly for patients with private insurance. Services are ‘resident focused’ and tailored to individual needs. Residents are encouraged to shape their end of life experience to suit their lifestyle, while receiving professional care.¹⁰⁷

In addition Hopewell provides services for children dealing with grief and loss, a holiday program for families with a child who has a terminal diagnosis, community training courses in grief and loss and palliative care, and after death services such as remembrance services and grief support groups. The Hospice has a team of over 100 trained volunteers.¹⁰⁸

Hopewell Hospice receives approximately one quarter of its funding from Queensland Health the remainder from fundraising and payments on behalf of privately insured patients.¹⁰⁹

- **Ipswich Hospice** has been operating for over 18 years, has seven inpatient beds, and also provides home care and respite care. In addition to the equivalent of 18 full time staff, the hospice has 270 volunteers. It works closely with the Ipswich Hospital and cares for approximately 80 to 90 patients a year. The hospice operates ‘Hilda’s House’ which provides bereavement for the community, including professionally facilitated peer support groups and children’s grief groups.¹¹⁰

Ipswich Hospice receives approximately half of its funding through Australian and Queensland Government grants.¹¹¹ The Hospice states that it generates more of its income each year from the community, including through donations, fundraising and private health insurance.¹¹²

- **Toowoomba Hospice** has six inpatient beds, and provides palliative care for terminally ill people from Toowoomba and the Darling Downs during the last three months of life. The model of service is individualised and holistic, and families and significant others are encouraged to be involved in day to day care. The Hospice has over 100 volunteers who provide administrative and ancillary services and are involved in fundraising.¹¹³

Toowoomba Hospice has been operating since 2003. It receives approximately one third of its funding from Queensland Health and the remainder from fundraising and payments on behalf of privately insured patients.¹¹⁴

- **Katie Rose Cottage** (Sunshine Coast Community Hospice) has six inpatient beds and provides support care for people from Gympie to Caloundra and surrounding areas. Hospice nursing and support services are free, and guests or their carers meet the cost of medical supplies and medication.

¹⁰⁶ Queensland Health, *Private Health Facilities list as at December 2012*, accessed 21 January 2013 from <http://www.health.qld.gov.au/privatehealth/>

¹⁰⁷ Hopewell Hospice Services Inc., Submission no. 27, pp.5–6

¹⁰⁸ Hopewell Hospice Services Inc., *ibid.*, pp.5–6

¹⁰⁹ Hopewell Hospice Services Inc., *ibid.*, p.10

¹¹⁰ Ipswich Hospice Care Inc., Submission no. 59, pp.2–6

¹¹¹ Ipswich Hospice Care Inc., *Annual Report 2011/12*, pp.24–5, available at <http://www.ipswichhospice.org.au/who-we-are/annual-report/>

¹¹² Ipswich Hospice Care Inc., Submission no. 59, p.3

¹¹³ Toowoomba Hospice Association Inc., Submission no. 21, pp.1–2

¹¹⁴ Toowoomba Hospice Association Inc., *ibid.*, pp.1–2

- **Townsville Palliative Care Centre** includes a 12 bed hospice in the grounds of the Townsville Hospital.

4.5.3 Hospice services in the home

A small number of services provide ‘hospice in the home’ to support palliative patients and their families. For example:

- **Karuna Hospice** in Brisbane’s northern suburbs, provides home-based interdisciplinary specialist palliative care services in the geographical area of the Metro North HHS. The service is a Level 3 palliative care service, in the CSCF. The service has a multidisciplinary team including nurses, social workers, bereavement support, counselling, pastoral and spiritual care staff. Medical services are provided by a general practitioner or palliative care specialist in a shared care arrangement. A team of trained volunteers also provide in-home support to clients and carers.¹¹⁵
- **Cittimani Hospice Service** provide hospice in the home services, including 24-hour on-call nursing, counselling and spiritual support, bereavement support, and loan of equipment for Sunshine Coast residents. A team of trained volunteers can provide carers with a break, including overnight. The service is free, and relies on donations.¹¹⁶
- **Little Haven Palliative Care** provides at home hospice service in Gympie and surrounding areas. Services include 24-hour on-call palliative care nursing, equipment loans, bereavement support and complementary therapy. A team of trained volunteers provide respite care and practical assistance in the home and garden. The service has strong links with Queensland Health, and its administrative base is in the grounds of Gympie Hospital.¹¹⁷

Hospices, their location and, where relevant, the number of beds is shown in Table 3 below.

Table 3: Queensland hospices, location and number of beds

Hospice	Location	Catchment area	No. beds
Cittimani	Palmwoods	Sunshine Coast and Hinterland (Landsborough and Caloundra in the south to Yandina and Coolumb in the north)	home-based care
Hopewell Hospice	Arundel	Gold Coast	8
Ipswich Hospice	Ipswich	Ipswich and West Moreton region	7
Karuna	Brisbane	Metro North District	home-based care
Katie Rose Cottage	Doonan	Sunshine Coast (Gympie to Caloundra and surrounding district)	6
Little Haven Palliative Care	Gympie	Gympie and surrounding region	home-based care
Toowoomba Hospice	Toowoomba	Toowoomba and the Darling Downs	6

Source: Cittimani Hospice Service, *Cittimani Hospice Service – Our Service Profile*; Hopewell Hospice Services Inc., Submission no. 27, p.5; Ipswich Hospice Care Inc., Submission no. 59, p.2; Karuna Hospice Service Ltd., Submission no. 13, p.3; Sunshine Coast Community Hospice, *Katie Rose Cottage – A Community Palliative Care Hospice*, accessed 13 May 2013 from <http://sunshinehospice.org.au/katie-rosecottage>; Little Haven Palliative Care, *Our Services*, accessed 13 May 2013 from <http://littlehaven.org.au/our-services/>; and Toowoomba Hospice, Submission no. 21, p.3

¹¹⁵ The Karuna Hospice Service Ltd., Submission no. 13, p.3

¹¹⁶ Cittimani Hospice Service, *Cittimani Hospice Service – Our Service Profile*, accessed 21 February 2013 from <http://www.cittamanihospice.com.au/index.html>

¹¹⁷ Queensland, Legislative Assembly, *Hansard*, 31 July 2012, p.1288 (David Gibson, Member for Gympie), available at http://www.parliament.qld.gov.au/documents/hansard/2012/2012_07_31_WEEKLY.pdf; and Little Haven Palliative Care, *Our Services*

4.6 General practitioners

Much of the palliative care that is provided occurs in the community, and medical care is primarily provided by general practitioners. Good palliative care at home can be delivered by general practitioners in conjunction with home nursing care and support services, support from a specialist palliative care team when needed, and access to inpatient care when required.¹¹⁸ While general practitioners play a critical role in palliative care at home, there are challenges associated with maintaining knowledge and skills, and in responding to client's need for after-hours care. Some of those issues are discussed in Chapter 12 of this report.

Given most people's preference to die at home or in place, home medical care is critical for palliative patients. Most GPs manage patients who are in the final stages of life and who have a range of chronic non-malignant conditions, and it is suggested many GPs are providing palliative care, even if that is not recognised by the GP.¹¹⁹

Data on the number of GPs who provide palliative care, and number of consultations is limited. In Australia in 2010–11, an estimated one in 1,000 GP encounters, or 108,325 encounters, were palliative care-related. Most of those GP encounters (73.7 per cent) were with patients aged 65 and over. Just over half of the GP encounters were in major cities (55.2 per cent), 29 per cent were in inner regional areas and 11.4 per cent were in outer regional locations. Only 4.4 per cent were in remote and very remote areas.¹²⁰ As noted above, GPs may not specifically identify some of the care they provide for older patients with chronic conditions as palliative;¹²¹ if this is correct, it is possible the national data may underestimate the extent of GP involvement in palliative care.

4.7 Palliative care for children

The Statewide Paediatric Palliative Care Service (PPCS) provides specialist services for children with a life limiting condition (where life expectancy is less than age 18). Queensland Health's submission stated that children up to 18, including perinatal patients,¹²² "...will require a general practitioner and paediatrician to oversee their care within the community".¹²³ The submission described the PPCS services as:

Within Brisbane, the PPCS is available to consult on children living in the metropolitan area and also complex cases outside of Brisbane when requested (this may be due to the complexity of the care or related to patients being referred back to a regional or rural centre from one of the tertiary hospitals).

Although the service is based at the [Royal Children's Hospital] in Brisbane, consultation and support is available throughout Queensland and northern New South Wales through the use of technology (telehealth). PPCS clinicians are able to provide the appropriate care and support in a timely manner and in the location that is most convenient to the family.¹²⁴

The PPCS also provides state-wide information and advice about palliative care.¹²⁵

¹¹⁸ Yuen KJ, Behrndt MM, Jacklyn C and Mitchell GK, 'Palliative care at home: general practitioner working with palliative care teams', *MJA*, September 2003, Vol.179, No.6, p.38

¹¹⁹ Professors Geoff Mitchell and Xavier Gomez-Batiste, Submission no. 52, pp.1 & 3

¹²⁰ AIHW, *Palliative care services in Australia* 2012, 2012, Canberra, p.32, available at <http://www.aihw.gov.au/publication-detail/?id=10737423073>

¹²¹ Professors Geoff Mitchell and Xavier Gomez-Batiste, *ibid.*, p.3

¹²² The perinatal period is from 20 weeks gestation to the 28th day of newborn life.

¹²³ Queensland Health, Submission no. 35, p.8

¹²⁴ Queensland Health, *ibid.*, p.11

¹²⁵ Queensland Health, *ibid.*, p.11

In addition, the committee was told about the palliative approach taken in the neonatal intensive care unit at Townsville HHS, where neonates who are terminally ill and their families are cared for in a room (the 'Butterfly Room') which is home-like, and separate from the intensive care of other newborn children.

4.8 Telephone and internet information and referral services

A free state-wide Palliative Care Helpline provides information about palliative care, contact details for local services, and specialist counselling and emotional support to clients, carers, families and friends. The Helpline was established in late 2000 as a pilot project to provide information to people who required palliative care services, along with their family, friends, carers and clinicians. The pilot was established by a consortium of public sector and non-government organisations.¹²⁶ The service operates during business hours out of Karuna Hospice, and is funded by Queensland Health.¹²⁷ It is staffed by nurses, social workers and counsellors, and supports over 1,500 callers annually.¹²⁸

The Australian Government Department of Health and Ageing funds *CareSearch*, which is an online information resource about palliative care. The website has sections designed specifically for health professionals and others for patients, for carers, and for family and friends.¹²⁹

Some palliative care services provide a 24-hour telephone on-call service for palliative patients of their service. For example, the Brisbane South Metro Palliative Care Service has a 24-hour service staffed by rostered nurses and doctors. The on-call service is supported by a web-based information system which allows real time access to palliative patient's clinical information. The Palliative Care Clinical Information System is described as the only one of its kind in Queensland,¹³⁰ and is discussed in more detail in Chapter 15.

4.9 Residential aged care facilities

An increasing proportion of older people live and die in residential aged care facilities (RACFs) each year, and many of those people would benefit from palliative care. With increasing rates of chronic disease and dementia in older people, RACFs (nursing homes and hostels) are an important setting for the provision of palliative care.

Some HHS palliative care services provide an 'in-reach' palliative care service to RACFs in the region. A service of this type has the potential to reduce the number of inappropriate referrals and admissions of RACF residents to emergency departments. This is discussed in Chapter 12.

¹²⁶ Palliative Care Helpline, *Palliative Care Helpline*, accessed 23 January 2013 from www.palliativecarehelpline.org.au/pchl-about-us

¹²⁷ Palliative Care Helpline, *ibid.*

¹²⁸ Palliative Care Queensland (PCQ), Submission no. 74, p.33

¹²⁹ CareSearch, *CareSearch palliative care knowledge network*, accessed 23 January 2013 from <http://www.caresearch.com.au/Caresearch/Default.aspx>

¹³⁰ Professor Liz Reymond, Submission no. 11, p.5

Chapter 5. Community care services and disability services

5.1 Introduction

The information in this chapter is based primarily on the *Manual for Queensland Community Care Services* published by the Department of Communities, Child Safety and Disability Services (Department of CCSDS). Additional material was provided by the Department in January 2013 in response to the committee's request for details of current Queensland disability programs and types of community care services, eligibility criteria, assessment of eligibility and need, and whether services are provided across Queensland or in specific geographical locations.¹³¹ The Department of CCSDS response is available on the committee's web page.¹³²

'Community care services' provide basic support services to people with a disability or condition (permanent or temporary) that restricts their day-to-day living, so that they can remain living at home. 'Specialist disability services' provide higher level support for people with a more severe, permanent disability and more complex needs. Some clients who receive specialist disability services may also receive community care services.

5.2 Community care services

The Department of CCSDS is responsible for administration of the Queensland Community Care program, which is the Queensland component of the former Home and Community Care (HACC) program. The Department of CCSDS advised the committee that, since the separation of Australian Government and State Government responsibilities in July 2012, NGO funding contracts with the Queensland and Australian Governments "have been aligned where possible to ensure there is minimum impact on service providers...".¹³³ At November 2012 there were over 200 organisations funded to provide Queensland Community Care Services through approximately 618 service providers, with a "presence across Queensland, including remote areas".¹³⁴

5.2.1 Eligibility and access to community care services

The target population for Queensland Community Care Services are people under 65 (or Aboriginal or Torres Strait Islander people under 50) who have a moderate, severe or profound disability or a condition which restricts their ability to carry out activities of daily living, and the unpaid carers of those people. In addition to those criteria, to be eligible for Queensland Community Care Services a person must be living in the community and have difficulty performing core activities of daily living due to functional limitations. The "core activities of daily living" are communication, self-care, and mobility. Core activity tasks include dressing, bathing or showering, preparing meals, house cleaning and maintenance and using public transport.¹³⁵ In addition, to be eligible for Queensland Community Care Services, a person must be "at risk of losing their independence without assistance from Queensland Community Care Services due to loss of functional ability or unsustainable living arrangements".¹³⁶

People who receive a similar service from other government funded programs are not eligible. For example, a person in a disability program accommodation support service where the provider receives funding to deliver similar services is not eligible for Queensland Community Care Services.

Clients may be charged a fee for community care services, based on their capacity to pay and a scale of fees appropriate to the client's level of income, amount of services used and the circumstances. A

¹³¹ Health and Community Services Committee, Letter to Michael Hogan, DCCSDS, 28 November 2012

¹³² See DCCSDS, Submission no. 76, p.7, available at www.parliament.qld.gov.au/hcsc

¹³³ DCCSDS, Submission no. 76, p.7

¹³⁴ DCCSDS, *ibid.*, p.8

¹³⁵ DCCSDS, *ibid.*, p.7

¹³⁶ DCCSDS, *ibid.*, p.7

draft HACC Fees Policy, originally developed by all governments, guides the way that fees are charged for Queensland Community Care Services.¹³⁷

5.2.2 Services provided

The Queensland Community Care program provides “a broad range of low-intensity, basic maintenance and support services to younger people with a disability, and to support their carers in their caring role”.¹³⁸ The table below summarises the types of service offered as part of Queensland Community Care Services.

Table 4: Queensland Community Care Services – summary of services available

Service group	Service types
Home care services	Domestic assistance (e.g. cleaning, washing and ironing) Personal care (e.g. bathing, dressing) Social support (e.g. assistance with shopping) Respite care (assistance to carer, who may or may not be present) Other food services (e.g. assistance with cooking a meal)
Coordinated care	Assessment (of eligibility, need for assistance, prioritising need) Client care co-ordination (e.g. implementing care plan, liaison with multiple service providers, reviewing care plan) Case management (coordinated planning and delivery of suite of services, from different providers, to client with complex needs) Counselling/support, information and advocacy (individual or group support/counselling, individual training or advice to assist person to cope, and information about local services)
Clinical and specialist care	Nursing care (by registered or enrolled nurse) Allied health care (at home or in a centre)
Centre-based day care	Centre-based day care (attendance at structured activities, excursions, transport to and from home)
Home modification	Home modification (e.g. handrails, ramps, mobility aids, minor renovations) Goods and equipment (loan or purchase) ¹³⁹ Home maintenance
Meals	Meals (prepared and delivered to the client)
Transport	Transport (excludes patient transport to medical or hospital treatment; can be direct, or indirect such as vouchers)

Source: Department of CCSDS, *Manual for Queensland Community Care Services*, 2012, pp.14–20, accessed 26 February 2013 from <http://www.communities.qld.gov.au/resources/disability/support-services/our-services/hacc/documents/community-care-manual-book.pdf>

Carers of eligible clients may also receive counselling, support, information and advocacy services.¹⁴⁰ Respite for carers is part of the ‘Home care services’ group, summarised in the table above. The committee does not have data on the number of clients who received respite care.

¹³⁷ DCCSDS, *Manual for Queensland Community Care Services*, 2012, p.21 and Appendix E, pp.48–9, accessed 26 February 2013 from <http://www.communities.qld.gov.au/resources/disability/support-services/our-services/hacc/documents/community-care-manual-book.pdf>

¹³⁸ DCCSDS, *ibid.*, p.5

¹³⁹ “Queensland community care does not generally purchase the goods and equipment service type because complementary programs exist such as the Medical Aids Subsidy Scheme (MASS).” DCCSDS, *ibid.*, p.19

¹⁴⁰ DCCSDS, Submission no. 76, p.8

5.2.3 *Community care services and palliative care*

Evidence to the committee indicated that there may be some confusion about whether people who have been diagnosed as palliative are able to receive Queensland Community Care Services. The Department of CCSDS's manual states:

*Specialist palliative care services are outside the scope of Queensland community care. Clients eligible for community care services, who require palliative care, can continue to receive community care's basic maintenance and support services, subject to their priority of need and the capacity of the service provider. Support is available to carers of eligible clients.*¹⁴¹

5.3 Clients of community care services

A profile of the 36,808 clients aged under 65 (or under 50 if Aboriginal or Torres Strait Islander) in 2010–11 was prepared for the Department of CCSDS by PricewaterhouseCoopers. Approximately 67 per cent of clients had a disability, seven per cent had a mental health condition, and approximately 25 per cent had a chronic disease.

Just over half of the clients (55 per cent) received services for less than one hour per month, approximately 44 per cent received services for between one hour a month and a few hours a week. Approximately four per cent were high level users who received more than one hour a day of services. About half of the high level users also received specialist disability services.¹⁴² The manual for organisations funded to deliver Queensland Community Care states that services are typically provided for up to five hours a week for each client.¹⁴³

Clients may access Queensland Community Care Services either directly with a local service provider, or through a regional 'Community Access Point', which does an initial assessment and refers clients to service providers.¹⁴⁴

5.3.1 *Specialist disability services*

In 2010–11, 16,653 clients received community support services, 9,334 received community access services and 5,191 received respite services. Almost 7,000 clients received accommodation support services; however some of those services were in residential settings such as group homes.¹⁴⁵

¹⁴¹ DCCSDS, *Manual for Queensland Community Care Services*, p.13

¹⁴² DCCSDS, Submission no. 76, p.8

¹⁴³ DCCSDS, *Manual for Queensland Community Care Services*, p.6

¹⁴⁴ DCCSDS, Submission no. 76, p.8

¹⁴⁵ DCCSDS, *ibid.*, p.13

Part 3 Palliative care in Queensland – future directions

The right care, at the right time, in the right place ...

Chapter 6. Capacity, adequacy and effectiveness of palliative care services

6.1 Introduction

The committee's terms of reference require it to consider the capacity and future need for services, and the effectiveness and efficiency of palliative care services. The committee has considered a significant body of evidence that supports its view that palliative care in Queensland can be improved by a move toward a more needs-based and person-centred approach. It is expected that, in the medium to long term, this will result in improved quality and more cost effective services.

This chapter discusses the capacity of services to meet current levels of need, effectiveness and efficiency, access to palliative care services, information services to improve access, and palliative care service standards and benchmarks.

Other aspects of service capacity, adequacy and effectiveness are discussed in later chapters. Chapter 7 includes projections of future need for palliative care services. Issues of service capacity and adequacy are discussed in the context of service planning and resourcing (Chapter 14), settings in which palliative care is provided such as primary care, residential aged care, and generalist services (Chapter 12).

The effectiveness of palliative care services in meeting the needs of specific population groups is discussed in sections about palliative care for children and adolescents (Chapter 8), Aboriginal and Torres Strait Islander people (Chapter 9), people from other cultural, language and lifestyle groups (Chapter 10), those in regional and rural Queensland (Chapter 11), and carers (Chapter 21). Some enablers of effective and efficient palliative care are discussed in Chapter 15 (*Telehealth, videoconferencing*), Chapter 12 (*access to suitable equipment*) Chapter 16 (*public awareness about palliative care, death and dying*) and in Chapter 17 (*advance care planning*).

Some of the evidence about efficiency of palliative care relates to co-ordination and collaboration between services. This is discussed in *Part 6 Collaboration and co-operation between services – opportunities for reform*.

6.2 Developing the capacity of Queensland's palliative care services

*We have to concern ourselves with the quality of life as well as its length.*¹⁴⁶

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with terminal 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.

Palliative care provides relief from pain and other distressing symptoms. It affirms life and regards dying as a normal process and intends neither to hasten nor postpone death. Palliative care integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death and to help the family cope during the patient's illness

¹⁴⁶ Dame Cicely Saunders was a doctor, nurse and social worker who developed a (then) new approach to pain management and holistic care of the dying; she established the United Kingdom's first modern hospice in 1967. Her work led to the development of palliative care and the hospice movement in the UK.

and in their own bereavement. It uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated. Palliative care will enhance quality of life, and may also positively influence the course of illness. It 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 complication.¹⁴⁷

This holistic palliative approach contrasts with many aspects of medicine and health care which include sometimes rapidly developing treatments and interventions that allow people to live longer with diseases than was previously possible. One submission described some of the challenges and strengths of palliative care in our health system in this way:

Today palliative care operates within a highly technologically driven healthcare system, where life can be maintained even in the absence of quality of life. This can create patient and family distress, clinical tensions and can generate unsustainable healthcare costs. Our society struggles to cope with conflicting challenges where, in spite of recognising human mortality, suffering is not tolerated and death can be viewed as a failure. Palliative care plays an important role in advocating for patients, families and healthcare systems to deal with these challenges, emphasising what is best for the individual patient within the overall context of their life. It is the core dimensions of care, compassion and humanity that are driving the increasing relevance of quality palliative care in modern healthcare delivery.¹⁴⁸

Queensland has some excellent palliative care services, which are delivered by specialist and primary care health services including general practitioners, community care services and residential aged care services, and by families and volunteers. However, access to services is highly variable, and some people who could benefit from palliative care are not currently able to access it.

6.3 Insufficient capacity to meet current needs for palliative care

6.3.1 Access to palliative care services

Palliative Care Australia highlighted access as one of the fundamental issues impacting on the capacity of palliative care to be effective in addressing needs.¹⁴⁹ Their submission stated that palliative care is “... extremely well done in some areas, but not available in others. That is really not a very equitable situation”.¹⁵⁰

Dr Luxford informed the committee that “very definitely your access [to palliative care services] is determined largely by your location, by your diagnosis, by the education of your health professional, by your cultural background and definitely by your age as well.”¹⁵¹ Equitable access to palliative care is affected by:

- times that care is available – care needs arise around the clock
- settings that care is available – home, community, hospice and hospital
- geographic location – access issues are compounded in rural and remote locations
- awareness and health literacy about death and dying
- availability of skilled health providers to provide the right type of care, in the right place, at the right time
- education for health professionals in palliative care

¹⁴⁷ WHO, *WHO Definition of palliative care*

¹⁴⁸ Professor Liz Reymond, Submission no. 11, p.8

¹⁴⁹ PCA, Submission no. 69, p.3

¹⁵⁰ Dr John Kastrissios, President, Greater Metro South Brisbane Medicare Local, *Public Hearing Transcript*, 22 August 2012, p.20

¹⁵¹ Dr Yvonne Luxford, Chief Executive Officer, Palliative Care Australia, *Public Hearing Transcript*, 22 August 2012, p.3

- high quality data to inform decisions about service delivery, assess current practice and the impact of efforts to improve services
- cultural competency – the influences of culture and ethnicity on care choices, and the cultural competency of health and care providers.

6.3.2 Service capacity does not meet current needs

Submissions and oral evidence indicated that the existing capacity of palliative care services is stretched. Palliative care service providers advised that they were insufficiently resourced to meet needs and provided a range of examples to illustrate this.¹⁵² Specialist services that operate are “understaffed, under-resourced, mostly have insufficient beds, and do not have the capacity to provide adequate community care and after-hours cover.”¹⁵³ Submissions noted that increasing demand for palliative care services (illustrated in particular by annual increases of 20 per cent in referrals to services) had not been met with increased resourcing.

Palliative Care Queensland (PCQ) advised the committee that specialist palliative care services were finding it a ‘struggle to cope’ as referrals to palliative care increased by more than 20 per cent each year.¹⁵⁴ For example, the number of patients cared for annually by the Supportive and Palliative Care Service of the Gold Coast Hospital and Health Service increased from approximately 200 patients in the community at any one time in 2008, to 390 by 2012. This is an approximate increase of 25 per cent a year.¹⁵⁵ Referrals to specialist palliative care services in Townsville increased by 30 per cent in six months in 2010, and during the last few years the referrals to the Sunshine Coast palliative care service have increased from an estimated 250 a year to 100 a month.¹⁵⁶

Submissions from palliative care providers told of the significant stress placed on palliative care services by existing levels of demand. Professor Rohan Vora advised the committee that the current level of service demand was ‘impossible to manage’.¹⁵⁷ A large provider of home-based palliative care services in Brisbane noted that need is already unmet and increasing.¹⁵⁸ Other service providers also reported that they are not able to meet current levels of demand for services.¹⁵⁹

6.3.3 Limits on access to services provided in response to increased demand

An increasing rate of growth in need without a commensurate increase in resources means that service providers must limit access and the amount and type of care that can be provided. In response to the pressures of unmet demand for services, some service providers have decided to not accept certain types of patient. For example, they may no longer provide access to non-cancer patients, residents of RACFs or patients with a prognosis of more than three months. Some services, including the Mater Palliative and Supportive Care Service, have also ceased home-visiting.¹⁶⁰

Demand for palliative care is increasing and specialist palliative care services have needed to:

*restrict their delivery to patients with specific diagnoses such as cancer or motor neurone disease, a short prognosis (e.g. less than 3 months of life expectancy) or patients who are in the community but excluding those in residential aged care facilities.*¹⁶¹

One submission suggested that each HHS should have a specialist palliative care service.¹⁶²

¹⁵² Metro North Hospital and Health Service, Submission no. 45, p.2

¹⁵³ PCQ, Submission no. 74, p.12

¹⁵⁴ PCQ, *ibid.*, p.9

¹⁵⁵ Professor Rohan Vora, Submission no. 73, p.4

¹⁵⁶ PCQ, *ibid.*, p.6

¹⁵⁷ Professor Rohan Vora, *ibid.*, p.4

¹⁵⁸ The Karuna Hospice Service Ltd., Submission no. 13, p.6

¹⁵⁹ Professor Liz Reymond, Submission no. 11, p.9

¹⁶⁰ PCQ, *ibid.*, p.9; Professor Janet Hardy and Decima Jones, Submission no. 16, p.4

¹⁶¹ PCA, Submission no. 69, p.11

6.3.4 Future needs

Chapter 7 sets out some projections of the future level of need for palliative care and the factors that contribute to increased need. Those needs cannot be met without significant work to develop the capacity of specialist, generalist, primary health care and community services, health professionals and care workers. Change is also needed to improve co-operation and collaboration between services to ensure that resources are used in the most effective way.

6.4 Effectiveness and efficiency of palliative care services

The effectiveness of palliative care services is best assessed according to whether it meets the needs of patients and their family and significant others, and how they fare after the patient dies. Research has confirmed that when asked where they would choose to die, more than 70 per cent of people choose home.¹⁶³ Some patients are not able to make a genuine choice to remain at home if the services available or their particular circumstances do not support it. If a person's needs are complex at the end of life, they may need to be admitted to hospital for a short time. It is important to recognise that for some people, end of life hospital care is necessary or may be their preference, but that most people's care needs can be managed in a non-specialist setting, and may not require hospitalisation.

What is important is that the palliative care available is the "right service, at the right place, at the right time". Queensland should aim to deliver palliative care which is:

- needs-based
- high quality, flexible and person-centred, sensitive to individual and cultural differences (the right service)
- accessible to all and delivered in the home and community, and across general and specialist areas of the health system (the right place), and
- provided early enough in a person's disease trajectory that care can be planned and the person's quality of life is maximised (the right time).

The evidence presented to the committee has led it to the view that palliative care should be based on needs, and should be person-centred. There is ample evidence that some of the most efficient and effective approaches to palliative care delivery are the approaches that patients want, because their needs and preferences are met. As well as providing services that meet patient's needs, further investment in appropriate palliative care has the potential to deliver both financial and operational benefits through the freeing-up of acute hospital beds.¹⁶⁴

6.5 Improving effectiveness and efficiency by providing needs-based and person-centred care

The best interest of the patient is the only interest to be considered. – William J. Mayo

6.5.1 Needs-based care

The committee accepts the views of many stakeholders that palliative care should be based on needs, both at the individual or family level, and at the state-wide level when planning and funding palliative care. State-wide and HHS planning and funding issues are discussed in Chapter 18.

¹⁶² Professor Liz Reymond, *ibid.*, p.8

¹⁶³ Scott Blackwell, National President, Palliative Care Australia, *Public Hearing Transcript*, 22 August 2012, p.4

¹⁶⁴ PCA, *ibid.*, p.10

6.5.2 Person-centred care

Person-centred care was supported by many stakeholders. Carers Queensland recommended that person-centred planning and service delivery be adopted as the norm by palliative care and community care service providers.¹⁶⁵

Some service providers are changing focus toward delivering person-centred services. For example, Blue Care launched its new service model 'Blue Care Tailor Made' in 2012 for its home care, palliative and residential care. The model "...places the person at the centre of all we do". The individual's unique needs and the role of their family and friends is recognised, and Blue Care aims to design services that are 'tailor made' to the individual, and delivered in a way that the person is in control rather than controlled.¹⁶⁶

Example 3: Needs-based and person-centred care

Silver Chain's Hospice Care Service in Western Australia delivers specialist community palliative care services and is regarded as a model of best practice. The service is staffed by specialist nurses, medical consultants, registrars, GPs, allied health professionals, care aides and volunteers. The model of care is client centred, home-based and aims to reduce unnecessary and undesirable hospital admissions. The approach is population based and uses different care pathways to respond to different needs. Care planning is interdisciplinary, and the service works to build families' capacity to care. The service reports client satisfaction of 98 per cent.¹

Sixty per cent of the Silver Chain's clients died at home, compared to a national average of 25 to 30 per cent. Of the clients who died at home, 60 per cent did not have any hospital admissions during their time with the hospice service, and 28 per cent had only one hospital admission.²

To provide a comparison for hospital admission outcomes, a study of hospital admissions of a sample of 1,071 people who died from conditions considered amenable to palliative care in Western Australia between August 2005 and June 2006, found that only four per cent of people did not have any hospital admissions. Seventy per cent of people presented at least once to a hospital emergency department, and made a total of 2,068 visits to emergency during their last year of life. Two-thirds (1,379) of those emergency department presentations resulted in hospital admission.³

¹ Australian Hospitals and Health Network, Submission 22, p.3

² Australian Hospitals and Health Network, Submission 22, p.3

³ Rosenwax, LK, McNamara, BA, Murray, K, McCabe, R, Aoun, SM and Currow, DC, 'Hospital and emergency department use in the last year of life: a baseline for future modifications to end-of-life care', *Medical Journal of Australia*, 2011, Vol. 194, No. 11, p.570

The home death rate of registered palliative care patients in Queensland is low, at an estimated 15–28 per cent, compared with 60 per cent elsewhere (see Example 3 above). Where 24-hour care is funded and provided, for example by the service at St Vincent's Brisbane, the home death rate is 50 to 60 per cent of patients.¹⁶⁷

6.5.3 Effectiveness of palliative care at home

Effective palliative care meets the needs of the patient and family. Given the diversity of the Queensland community and the varying circumstances of palliative care patients, effective palliative care must have the flexibility to respond to diverse and changing needs. Models of care that are person-centred appear to maximise patient choice and provide flexibility to meet patient needs.

Over 70 per cent of patients would prefer to be cared for at home in the last year of life. Many of those patients, however, currently attend hospital emergency departments and are admitted to acute care wards,¹⁶⁸ possibly because of worsening symptoms or uncertainty about the person's wishes about care as they approach the end of life. By avoiding inappropriate and preventable

¹⁶⁵ Carers Queensland, Submission no. 9, p.12

¹⁶⁶ Blue Care and UnitingCare Health, Submission no. 24, p.7

¹⁶⁷ PCQ, Submission no. 74, p.9

¹⁶⁸ PCA, Submission no. 69, p.3

admissions to emergency departments and acute wards, patients' quality of life may be enhanced, freeing-up the Emergency Department and acute wards for other operational use.

Queensland Health advised the committee that:

*There is an emerging outcomes based and health economic literature that suggests that early referral to specialist palliative care leads to higher patient satisfaction, more appropriate care in the setting of choice, better quality of life for patients and families and cost efficiencies for the health system.*¹⁶⁹

Metro North HHS drew the committee's attention to a Western Australian study¹⁷⁰ that found that those who accessed community based specialist palliative care had a seven times higher chance of dying in their usual place of residence. This indicates the potential to reduce hospital admissions through better community based palliative care.¹⁷¹

In recent years the palliative care service at Gold Coast Hospital and Health Service has placed more medical time in the community rather than with inpatients. The rate of deaths of palliative care patients at home is an indicator of the extent to which patient's preferences are met, and of delivery of cost effective care. Deaths at home have increased from approximately five per cent in 2008, to 16 per cent in 2012.¹⁷² With more focus on care in the community, for example, by providing resources for "bed equivalents" and contracting services from non-government organisations, more people could be supported to die at home if that was their choice.

A submission from clinicians at the Mater Health Services Palliative and Supportive Care Department highlights the benefits that were derived when a specialist palliative care service delivered home-based services. In response to increased demand on services, home visits and on-call after hours telephone support have ceased. "This has led to an increase in admissions, especially after hours and at weekends."¹⁷³

6.5.4 Cost effectiveness of palliative care at home

Estimates of the cost of palliative care in different settings are shown in Table 5 below.

Table 5: Estimated cost of palliative care in different settings

	Estimated cost
acute hospital bed	\$1,100 per day
ambulance callout	\$300 – \$5,000 per callout
palliative care at home	no Australian estimate located ¹⁷⁴
palliative care in residential aged care facility (average for high care residential aged care)	\$200 per day
palliative care in a hospice	\$600 per day
inpatient palliative care facility	\$950 per day
intensive care unit bed	\$4,000 per day

¹⁶⁹ Queensland Health, Submission no. 35, p.7.

¹⁷⁰ McNamara B and Rosenwax L, 'Factors Affecting Place of Death in Western Australia', *Health & Place*, 2007, Vol.13, No.2, pp.356–67

¹⁷¹ Metro North Hospital and Health Service, Submission no. 45, p.3

¹⁷² Professor Rohan Vora, Submission no. 73, p.4

¹⁷³ Professor Janet Hardy and Decima Jones, Submission no. 16, p.4

¹⁷⁴ A Canadian study testing a 'shared care' model of rural palliative care at home found the average cost was approximately \$120; the costings may not be directly comparable to Australia (Klinger CA, Howell D, Marshall D, Zakus D, Brazil K and Deber RB, 'Resource utilization and cost analyses of home-based palliative care service provision: the Niagara west end-of-life shared-Care Project', *Palliative Medicine*, February 2013, Vol.27, No.2, pp.115–22, cited in: Hodgson C, *Cost-effectiveness of Palliative Care: a review of the literature*, 2012, available at <http://hpcintegration.ca/media/24434/TWF-Economics-report-Final.pdf>)

Palliative Care Queensland noted the significant cost difference between an acute hospital bed, at an average of \$1100 per day, and \$950 per day for inpatient palliative care. Acute hospital beds could be available for other patients, and patients and families have access to a preferred place for end-of-life care.¹⁷⁵

In evidence to the committee, Professor Rohan Vora of the Royal Australian College of Physicians suggested that health services:

*... are suffering under the cultural belief that maybe, if they do not worry about palliative care, it will all just go away. They do not necessarily see it as a priority; however, these patients end up in emergency and in acute care beds.*¹⁷⁶

St Vincent's Hospital noted that the general resources needed to keep patients at home are not available. Home packages of care are needed that can be tailored to each individual situation. Too few packages are currently available to palliative patients and many do not provide sufficient support.¹⁷⁷ Professor Vora's submission argued that the resourcing of appropriate palliative care would free up acute hospital beds and decrease the number of accident and emergency presentations.¹⁷⁸

St Vincent's Brisbane noted the importance of 24-hour community care in ensuring patients can die at home, if they choose. In its experience, few specialist palliative care services across the state have the capacity to offer 24-hour community care, even on a consultation basis to generalist services.

Blue Care suggested that community based palliative care funding should be "able to be accessed directly by the organisation providing care, rather than brokered through the local hospital and should not be determined by estimated prognosis". It suggests staged funding on diagnosis, "according to need and flexible enough to incorporate clinical care (nursing and allied health), after hours care and lifestyle support".¹⁷⁹

At the public hearing, Professor Vora suggested that funding of palliative care services should be based on evidence based outcomes, and purchased via hospital consultancy liaison teams that would be able to shift care from acute care to palliative care and out into the community. This could achieve "a major shift of a lot of acute care patients into a palliative and subacute framework".¹⁸⁰ In its submission to the committee, Karuna Hospice also recommended that there be a redistribution of funding for palliative care from hospitals to community care.¹⁸¹ Palliative Care Queensland also noted the importance of funding specialist palliative care consultancy-liaison services in order to properly support palliative care outside hospitals.¹⁸²

The committee believes that this could be a very positive avenue to pursue as part of developing a new approach to funding for palliative care in Queensland. Significant funding efficiencies could be realised while meeting patient and family preferences for dying at home rather than in hospital, when this is possible.

¹⁷⁵ PCQ, Submission no. 74, pp.9–10

¹⁷⁶ Professor Rohan Vora, RACP, *Public Hearing Transcript*, 22 August 2012, p.12

¹⁷⁷ St Vincent's Hospital Brisbane, Submission no. 44, p.5; also Professor Liz Reymond, Submission no. 11, p.18; and Professor Rohan Vora, Submission no. 73, p.7

¹⁷⁸ Professor Rohan Vora, *ibid.*, p.2

¹⁷⁹ Blue Care and UnitingCare Health, Submission no. 24, p.18

¹⁸⁰ Professor Rohan Vora, RACP, *Public Hearing Transcript*, 22 August 2012, p.13

¹⁸¹ The Karuna Hospice Service Ltd., Submission no. 13, p.8

¹⁸² PCQ, Submission no. 74, p.9

6.6 Palliative care information and telephone support services

6.6.1 Types of palliative care telephone services

A common theme in submissions and evidence at hearings was the importance of readily accessible 24-hour information and support services for patients and their families or carers. Witnesses drew a distinction between information, referral and support services on one hand, and access to 24-hour specialist clinical support and advice for palliative care patients and their carers, for example, when a patient's symptoms change rapidly. The two types of service are:

- a state-wide 24-hour telephone information, referral and support service to provide information about palliative care and related services in the callers region, support and information about what to expect from palliative care services, and an opportunity to talk about their illness and dying. "... (P) eople are more likely when they are first diagnosed with a palliative condition to have that deidentified, anonymous kind of conversation about what this might mean for them if it is a call line."¹⁸³
- access to 24-hour (local or regional) specialist palliative care clinical support and advice, where the family of registered patients who are at home can contact their specialist palliative care service for advice, and if needed, for a home visit. For example, the Brisbane Metro South HHS specialist palliative care service (a Level 6 public sector service¹⁸⁴) provides 24-hour access to a member of the treating team who they know, who can prescribe (i.e. a doctor or a nurse practitioner) and advise about medication and if necessary, arrange admission to a palliative care hospital bed.¹⁸⁵ Karuna Hospice also provides 24-hour specialist palliative care service where staff "... are on call-out and not just to answer calls. The interesting thing about that is that only one out of every six after hours calls actually results in the nurse having to go to the call-out and most of those visits are actually because it is the end of life".¹⁸⁶

The committee considers that the latter type of service should be part of the specialist palliative care service provided by HHSs, and this is discussed in Chapter 13.

An information, referral and support service could operate state-wide, provide links to local services, provide skilled counselling and support services, and be accessible to all. In contrast, 24-hour clinical support services would operate in a HHS or region, provide clinical advice and support for existing patients of a palliative care service, and ideally be supported by a 24-hour home visiting service. The Metro South palliative care service provides a good example of this type of 24-hour clinical assistance.

6.6.2 State-wide 24-hour information and support telephone service

A free state-wide Palliative Care Helpline currently operates, and is funded by Queensland Health. It provides information about local services, and offers support to callers, but operates only during business hours (see 4.8 above).

Ms Hope suggested that a 24-hour information and support service would be best as a specific palliative care specific service.¹⁸⁷ Other witnesses emphasised the different roles between a state-wide telephone service to provide information, support and links to regional services for referrals, for example for newly diagnosed patients, and the more intensive 24-hour on-call clinical service needed

¹⁸³ Glenys Webby, *Public Roundtable Discussion Transcript*, 14 November 2012, p.6

¹⁸⁴ See Table 1: Summary of palliative care service levels in the Clinical Services Capability Framework on page 22

¹⁸⁵ Professor Liz Reymond, Clinical Director, Metro South Palliative Care Services, *Public Roundtable Discussion Transcript*, 14 November 2012, p.4

¹⁸⁶ Catherine Mickel, Chairperson, Karuna Hospice, *Public Roundtable Discussion Transcript*, 14 November 2012, p.4

¹⁸⁷ Carol Hope, Advocacy And Clinical Development Leader, Karuna Hospice, *Public Hearing Transcript*, 24 August 2012, p.17

for patients of a palliative care service, where clinical advice tailored to the individual patient is required.¹⁸⁸

The committee considers that a 24-hour state-wide telephone information and support service is required. A telephone information and support service should be able to offer up to date information about local services, and skilled support and counselling about death, dying and palliative care. When relevant, the service should be able to transfer callers directly to a local or regional 24-hour palliative care service to ensure that access to local services is facilitated.

Recommendation 1 – 24-hour state-wide telephone service

The committee recommends that the Minister for Health provide resources as soon as possible for a 24-hour state-wide palliative care telephone information, referral and support service, staffed by skilled nursing and allied health staff, and supported by an internet information service by, for example, incorporation into 13 QGOV.

6.7 Palliative care standards and benchmarks

6.7.1 National palliative care standards

The national palliative care standards developed by Palliative Care Australia (PCA) “reflect as far as possible the level of care that the Australian community would expect, when faced with a life limiting illness”.¹⁸⁹ There are 13 quality standards and the document provides guidance on implementation in primary health care and specialist palliative care settings. The foreword notes that the standards should be read in conjunction with PCA policy documents, *A Guide to Palliative Care Service Development: A population based approach*, and *Palliative Care Service Provision in Australia: A Planning Guide*. These ensure “consistent advice and direction to the health care sector”.¹⁹⁰

6.7.2 Benchmarking palliative care outcomes

Benchmarking of palliative care outcomes is undertaken by a national voluntary program, the Palliative Care Outcomes Collaboration (PCOC), funded by the Australian Government. Its aim is to assist palliative care providers to improve practice and meet the palliative care standards.

The PCOC provides a continuous quality improvement process for palliative care service providers,¹⁹¹ and works with palliative care service providers to:

- develop consistency in the collection of information
- provide evidence through the collection and analysis of information
- assist with quality and standards reporting
- provide a benchmarking service, and
- promote and support palliative care research.¹⁹²

¹⁸⁸ For example, *Public Roundtable Discussion Transcript*, 14 November 2012: Professor Liz Reymond, Clinical Director, Metro South Palliative Care Services, pp.4–5; Professor Judy Wollin, Quality and Research, Wesley Mission Brisbane, p.5; and Glenys Webby, Director, Strategy and Service Planning, Blue Care, p.6

¹⁸⁹ PCA, *Standards for Providing Quality Palliative Care for all Australians*, 4th edn, 2005, p.8, available at <http://www.palliativecare.org.au/Portals/46/Standards%20for%20providing%20quality%20palliative%20care%20for%20all%20Australians.pdf>

¹⁹⁰ PCA, *ibid.*, p.8

¹⁹¹ Palliative Care Outcomes Collaboration, *Palliative Care Outcomes Collaboration*, accessed 1 March 2013 from <http://www.pcoc.org.au/>

¹⁹² Palliative Care Outcomes Collaboration, *ibid.*

In 2009, PCOC and the participating service providers developed a set of national quality and outcome measures and benchmarks for palliative care provision. The four outcome measures are:

- time from referral to first contact (responsiveness),
- time in the unstable phase (timely management of acuity),
- change in pain (pain management),
- change in symptoms relative to the national average.¹⁹³

Services that can demonstrate the provision of clinical care to palliative care patients after a formal clinical assessment by a multidisciplinary team are eligible to join PCOC. The PCOC receives data on patient numbers, episodes of care (inpatient and community/ambulatory care) and palliative care phases and reports on each of the benchmarks every six months on a national and state and territory basis.

The four university palliative care research centres that make up the PCOC, and their chief investigators are:

- University of Wollongong – PCOC Central (Professor Kathy Eagar)
- University of Western Australia – PCOC West (Assistant Professor Claire Johnson)
- Flinders University, South Australia – PCOC South (Professor David Currow)
- Queensland University of Technology – PCOC North (Professor Patsy Yates).

The PCOC anticipates that a range of research opportunities will evolve as palliative care data is collected and analysed. Palliative care service providers benefit from benchmarking and feedback that provides a basis for quality improvements.

6.7.3 Reported improvements from benchmarking palliative care outcomes

Nationally, 103 services provided data to PCOC for the last published reporting period (July to December 2012) and PCOC estimates that over three-quarters of patients seen by specialist palliative services are included in their data collection.¹⁹⁴ In Queensland, 33 out of 44 palliative care services were collecting data at the end of 2011 and another two services had agreed to join PCOC.¹⁹⁵ This is a comparatively high proportion of participation compared to the other states and territories. The PCOC data highlights variation in the quality of palliative care being provided across Queensland and the need for a systematic approach to improvement in service quality and efficiency.¹⁹⁶

Improvements in clinical practice have been reported for service providers participating in PCOC. Practice improvements have followed from the use of standardised validated clinical assessment tools, the development and use of common clinical language and the collection of nationally consistent information about patient acuity, episodes (location) and phases of care. National benchmarking, the identification of service performance achievements and gaps and the opportunity to network, collaborate and share knowledge for service providers, have also supported quality improvement opportunities for providers, based on best practice and evidence.¹⁹⁷

While Queensland has a relatively high rate of participation in PCOC, the committee considers there would be merit in all specialist palliative care services participating in national benchmarking, to drive quality improvement and collaboration.

¹⁹³ Palliative Care Outcomes Collaboration, *Quality improvement through benchmarking palliative care outcomes*, brochure, available at <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow110669.pdf>

¹⁹⁴ Palliative Care Outcomes Collaboration, *National Report on Patient Outcomes in Palliative Care in Australia July – December 2012*, Report 14, March 2013, accessed 9 May 2013 from <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow148641.pdf>, p.2 and AIHW, *Palliative care services in Australia 2012*, p.74

¹⁹⁵ Professors Patsy Yates and Ross Young, Submission no. 65, p.3

¹⁹⁶ Professors Patsy Yates and Ross Young, *ibid.*, p.3

¹⁹⁷ Palliative Care Outcomes Collaboration, *ibid.*

Recommendation 2 – Participate in Palliative Care Outcomes Collaboration

The committee recommends that the Minister for Health:

- ensure that all public sector specialist palliative care services participate in and provide data to the Palliative Care Outcomes Collaboration (PCOC), and
- that Queensland Health publishes PCOC state-wide data on palliative care effectiveness.

The committee recommends that the Minister for Health:

- through the Chief Health Officer, encourage all private health facilities that provide specialist palliative care to participate in and provide data to PCOC
- encourage other specialist palliative care providers to participate in and provide data to PCOC.

Chapter 7. Future need for palliative care services

*People only die once. They have no experience to draw upon.*¹⁹⁸

7.1 Current and growing need for services

Evidence to the committee highlighted significant current unmet need for palliative care services that is growing and can be expected to continue to grow. The level of need for palliative care services is not able currently to be met by specialist palliative care services and primary health care services. The mismatch between current needs and current service capacity is discussed in section 6.3 above. A number of factors which drive expected higher levels of need for palliative care in the future are discussed below.

7.2 Demographic change

The need for palliative care services in Queensland is expected to continue to increase. Queensland's population is over 4.5 million and grew by 1.9 per cent between 2011 and 2012. Queensland's population growth rate continues to be higher than the national average (1.6 per cent) and has had the second largest population increase behind Victoria.¹⁹⁹

In line with the national trend, Queensland's population is ageing as a result of sustained low fertility (despite an increase in births in recent years), increasing life expectancy and movement of the large baby boomer cohort (born 1946–1965) into older age groups.²⁰⁰ In 2011, 14 per cent of Australia's population was aged 65 or older. By 2031, the Australian Bureau of Statistics predicts that 19–21 per cent of the Australian population will be 65 or older.²⁰¹ Life expectancy is also increasing.²⁰²

Palliative Care Queensland provided the committee with the following projections of annual referrals to specialist palliative care. The projections are based on data from the Office of Economic and Statistical Research, and Palliative Care Australia's guide to planning the provision of palliative care services.²⁰³

Table 6: Projected annual referrals to specialist palliative care 2010–2050

2010	2020	2030	2040	2050
11 834	14 378	17 009	19 645	22 320

Source: Palliative Care Queensland, Submission 74, p.19

The projected number of referrals to specialist palliative care services represents only a part of the potential future need for palliative care services. A significant proportion of people who receive palliative care are not referred to specialist services, but receive their care from GPs, primary health care providers or other medical specialities.

¹⁹⁸ Giffin M, 'Let's talk about dying', *Quadrant*, October 2011, pp.101–7, p.107

¹⁹⁹ Queensland Treasury and Trade, *Population Growth Highlights and Trends, Queensland*, February 2013, Government Statistician, p.1, available at <http://www.oesr.qld.gov.au/products/publications/pop-growth-highlights-trends-qld/pop-growth-highlights-trends-qld-2013.pdf>

²⁰⁰ Queensland Treasury and Trade, *ibid.*, p.4

²⁰¹ Health and Community Services Committee, *Inquiry into palliative care services and home and community care services in Queensland*, Issues Paper, June 2012, footnote 3, available at <http://www.parliament.qld.gov.au/documents/committees/HCS/2012/PalCareHAAC/IP-120626.pdf>

²⁰² Queensland Treasury and Trade, *ibid.*, p.4

²⁰³ PCQ, Submission no. 74, p.19

7.3 Changing disease patterns

At the same time that the population is ageing and growing, the incidence of chronic disease is increasing. This is due in part to the ageing of the population, but also to medical advances in disease treatment and management.

The leading causes of death in Australia are mainly chronic diseases.²⁰⁴ Chronic diseases include cardiac, respiratory, neurological and renal conditions. In 2007, chronic diseases were the cause of 83 per cent of all premature deaths (that is, deaths under the age of 75).²⁰⁵ Queensland Health advised the committee that patients are now living longer with much higher rates of chronic disease. They are “more likely to die from end stages of advanced chronic illness rather than short-term acute illness or injury as they had done in the past”.²⁰⁶ The Royal College of Australasian Physicians explained to the committee that medical technology had enabled more patients to live with complex and chronic diseases.²⁰⁷

While cancer is the most common principal diagnosis related to palliative care provision in hospitals (60 per cent), within the non-cancer diagnoses, heart failure and chronic pulmonary disease were the most frequently reported diagnoses.²⁰⁸

7.4 Variations in palliative care trajectories

Developing initially out of concern for cancer patients’ experience at the end of life, palliative care services have historically had strong links to cancer services and not to those related to major chronic diseases. Generally, the palliative care ‘trajectory’ experienced by cancer patients has been a short period of evident decline. In contrast, chronic diseases, such as those relating to the heart and lung, have a different trajectory, with patients experiencing long-term limitations and ‘intermittent serious episodes of decline’. In the case of frailty and dementia, conditions associated with ageing, there is a different palliative care trajectory again, that of prolonged decline.²⁰⁹

In its 2008 *Palliative and End of Life Care Glossary of Terms*, Palliative Care Australia noted that palliative care services, originally established to provide care to cancer patients, now needed to respond to patients with varying diagnoses and that new language was required to address this.²¹⁰

Different palliative care trajectories mean that patients need to access and use palliative care in different ways, creating a different pattern of demand for palliative care services to that experienced in the past. A number of submissions noted that, although the incidence of chronic disease and dementia is increasing, access to palliative care is not meeting needs for people with non-malignant diseases.²¹¹ There are also less clear transitions to palliative care for patients with chronic disease; instead there are long periods where ‘both interventional care and a palliative approach are needed’.²¹²

²⁰⁴ ‘Chronic disease accounts for more than half of all Australian deaths’. Burgess TA, Braunack Mayer AJ, Crawford GB and Beilby JJ, ‘Meeting end-of-life care needs for people with chronic disease: palliative care is not enough’, *MJA*, March 2013, Vol.198, No.4 p.186–7

²⁰⁵ AIHW, *Australia’s Health 2012*, 2012, Canberra, p.92, available at <http://www.aihw.gov.au/publication-detail/?id=10737422172>

²⁰⁶ Queensland Health, Submission no. 35, p.2

²⁰⁷ Professor Ann Rudden, Member, Queensland State Committee, The Royal Australasian College of Physicians, *Public Hearing Transcript*, 22 August 2012, p.11

²⁰⁸ Queensland Health, *ibid.*, p.2

²⁰⁹ Victorian Department of Health, *Strengthening Palliative Care: Policy and strategic directions 2011–2015*, p.38, available at http://www.health.vic.gov.au/palliativecare/documents/palcare_policy1114.pdf

²¹⁰ PCA, *Palliative and end of life care: Glossary of terms*, 1st edn, 2008, p.2, available at <http://www.palliativecare.org.au/Portals/46/PCA%20glossary.pdf>

²¹¹ The Karuna Hospice Service Ltd., Submission no. 13, p.5; Professors Patsy Yates and Ross Young, Submission 65, p.5

²¹² Burgess, Braunack Mayer, Crawford and Beilby, ‘Meeting end-of-life care needs for people with chronic disease: palliative care is not enough’, p.186

Even well understood palliative care trajectories, such as those for people with cancer, are requiring adjustment as new treatment options prolong life while increasing chronic (complex and severe) symptoms.²¹³ These changes increase the need for palliative care services and change patterns of demand.

The needs of people with progressive neurological conditions such as MS (multiple sclerosis) may vary considerably between individuals, and the course of MS is commonly unpredictable. A person's needs for palliative care may fluctuate and extend over a longer period than for other conditions, highlighting the importance of a flexible service system.²¹⁴

Variations in palliative care trajectories make the planning, funding and management of palliative care even more complex. This, in conjunction with historical funding arrangements and structures based on cancer services that require review, adds to the likelihood that palliative care service provision is inequitable.²¹⁵

Professor Liz Reymond of the Metro South HHS specialist palliative care service noted that 'the rapidly changing dynamics of palliative care demand' also means that traditional models for the provision of palliative care and funding are no longer useful.²¹⁶

7.5 Changing public expectations

Adding to the pressures of changing demographics and patterns of disease are the changing expectations of palliative care support from patients and families. There is a greater focus on the amount and quality of palliative care provided and higher expectations for individual needs and preferences to be met. The appropriateness of care, preferred place of death and equity of access to care are becoming increasingly important and people wish to be involved in decision making about their palliative care.²¹⁷ These expectations are, for many people in Queensland, not being well met by the current systems and structures.

In particular, people have a preference to die at home but less than half are able to do so in Queensland.²¹⁸ The existing structures and current funding levels result in palliative care services that do not have the capacity to better support patients and enable people to choose to die in place if they wish.²¹⁹ Existing models of palliative care provision are also challenged by the decreasing availability of family members and friends to act as unpaid carers.²²⁰

The Australian Healthcare and Hospitals Association summed it up like this:

*The majority of people want to be cared for and die at home – yet because of inequitable access to high quality community-based palliative care services across Australia, most will die in institutional settings. This is a poor outcome for these patients and their families, but it is also an inefficient and costly outcome for our health system.*²²¹

²¹³ Professor Janet Hardy and Decima Jones, Submission no. 16, p.4

²¹⁴ Multiple Sclerosis Society of Queensland, Submission no. 61, pp.1–2

²¹⁵ PCA, Submission no. 69, p.7; Professors Patsy Yates and Ross Young, Submission no. 65, p.2 and p.5

²¹⁶ Professor Liz Reymond, Submission no. 11, p.3

²¹⁷ AIHW, *Trends in palliative care in Australian hospitals*, 2011, Canberra, p.1, available at <http://www.aihw.gov.au/publication-detail/?id=10737420167>; Professors Patsy Yates and Ross Young, Submission no. 65, p.2; Professor Ann Rudden, *Public Hearing Transcript*, 22 August 2012, p.11

²¹⁸ The Karuna Hospice Service Ltd., *ibid.*, p.5

²¹⁹ Professor Rohan Vora, Submission no. 73, p.6

²²⁰ Professor Janet Hardy and Decima Jones, *ibid.*, p.4

²²¹ Australian Healthcare and Hospital Association, Submission no. 22, p.5

Taken together, changes in demographics, disease patterns and community expectations indicate that the future will see an ongoing and growing need for palliative care as well as a need for greater diversity in its provision.²²²

7.6 Groups with particular needs

In addition to the expectation of growing future need for palliative care, evidence heard by the committee also highlighted the significant numbers of patients who do not currently receive specialist palliative care and who probably should.²²³ Other submissions noted particular groups of people for whom palliative care was not well provided or was not available. These people included Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse backgrounds, people living in rural and regional areas, and children and adolescents. The particular needs of these groups with respect to palliative care and its provision are addressed in later chapters.

7.7 Better palliative care in residential aged care facilities

Older people and, in particular, those older people living in aged care facilities, are a significant group identified in evidence to the committee for whom palliative care needs are not adequately met.²²⁴

The need for a stronger focus on aged care residents has been recognised in recent years as part of the health reform agenda as well as aged care reforms.²²⁵ In its final report in 2009, the National Health and Hospitals Reform Commission recommended strengthening access to specialist palliative care services for people living in residential aged care facilities (RACFs).²²⁶ In reporting on its inquiry into care for older Australians, the Productivity Commission drew attention to the need for better palliative care to be provided in RACFs. Subsequently, the Australian Government's 2012 *Living Longer Living Better* Aged Care Reform package responded to those concerns by providing funding for specialist palliative care and advance care planning advice to aged care providers and GPs caring for aged care residents.

Unmet need for palliative care in RACFs places costly burdens on hospital emergency departments and acute care beds. Building a greater capacity for palliative care to be provided 'in place' for residents of aged care facilities and reducing unnecessary transfers to acute hospital care would improve end-of-life outcomes for older patients and assist in constraining acute care costs.²²⁷

There are no specific standards for the provision of palliative care in residential aged care other than those applying generally. *Guidelines for a palliative approach in residential aged care* were approved by the National Health and Medical Research Council in 2005. The guidelines aim to provide support and guidance to RACFs in delivering care that incorporates a palliative approach.²²⁸

Submissions from specialist palliative care service providers emphasised the need for specialist palliative care support for RACFs to be provided in tandem with better training for RACF staff in a palliative approach. At the same time, those submissions often expressed concern that the pressures of meeting demand for palliative care services in general usually meant that 'in-reach' to RACFs by specialist services was limited.

²²² AIHW, *ibid.*, p.1

²²³ RACP, Submission no.25, p.3

²²⁴ RACP, *ibid.*, p.3, Professor Rohan Vora, Submission no. 73; and Professor Liz Reymond, Submission no. 11

²²⁵ Professor Liz Reymond, *ibid.*, p.12

²²⁶ National Health and Hospitals Reform Commission, *A healthier future for all Australians – Final Report*, June 2009, accessed 20 March 2013 from <http://www.health.gov.au/internet/nhhrc/publishing.nsf/content/nhhrc-report>

²²⁷ Dr Mark Deuble, *Public Hearing Transcript*, 24 August 2013, p.29

²²⁸ NHMRC, *Guidelines for a Palliative Approach in Residential Aged Care*, p.1

The Royal Australasian College of Physicians noted that there are 'a number of exceptional local initiatives operating to link specialist palliative care services into RACFs'.²²⁹ Other initiatives are using the expertise of specialist palliative care services to assist in building the capacity to deliver high quality care at the end of life in Australian RACFs. One of these is the Palliative Approach Toolkit for RACFs developed by the University of Queensland/Blue Care Research and Practice Development Centre. The toolkit comprises modules covering how to integrate a palliative care approach, key processes for implementation and clinical care as well as self-directed learning packages for RACF staff, educational DVDs and flipcharts and resource materials.²³⁰ The toolkit is now being rolled out nationally by the Australian Government through a consortium led by the Brisbane South Palliative Care Collaborative.

The committee's recommendations about improving palliative care in RACFs are in Chapter 12 and Chapter 13.

²²⁹ RACP, *ibid.*, p.5

²³⁰ The University of Queensland / Blue Care Research and Practice Development Centre, *Palliative Approach Tool Kit*, accessed 7 January 2013 from <http://www.uq.edu.au/bluecare/the-palliative-approach-toolkit>

Chapter 8. Palliative care for children and adolescents

*Imagine the process of watching your child die and not knowing if their journey will be days, weeks, months or years ...*²³¹

8.1 Capacity and adequacy

The expected death of a child or adolescent is felt particularly intensely by family and friends, and the needs of children, adolescents and their families differ significantly from the needs of an adult with a terminal condition. Submissions from parents of children with life-limiting conditions indicate that when they have received services, including from individual paediatricians and the Paediatric Palliative Care Service (PPCS), it has been excellent.²³² However, submissions highlighted some significant gaps in information about services, the services available for children and adolescents – particularly respite services, hospice care and access to bereavement support and counselling.

8.1.1 Definition

In addition to the general definition of palliative care (see section 4.1 and glossary) the WHO defines palliative care appropriate for children and their families:

- care that is the active total care of the child's body, mind and spirit, and also involves giving support to the family
- care that begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease
- health providers must evaluate and alleviate a child's physical, psychological, and social distress
- effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited
- care can be provided in tertiary care facilities, in community health centres and the home.²³³

8.1.2 Factors that impact on the capacity and effectiveness of palliative care services for children and adolescents

The palliative care needs of adolescents and children (including very young infants) differ from adults in ways that impact on the way services are delivered and the capacity of services to meet needs. Those differences include:

- many individual life-limiting conditions are extremely rare, and the diagnoses are specific to childhood, although the child may survive into early adulthood
- the timescale of children's illnesses is different and uncertain; palliative care may last only a few days or months, or extend over many years
- some illnesses may affect more than one child in the family
- the specific nature of bereavement support for the family
- the continuing physical, emotional and cognitive development of children means that healthcare providers need to be aware of and responsive to a child's changing levels of communication and understanding of their illness, and
- the provision of education and play when a child is sick is essential²³⁴

²³¹ Paul Quilliam, Co-founder and Chairman, Queensland Kids, *Public Hearing Transcript*, 22 August 2012, p.16

²³² Brett and Louise Carter, Submission no. 30, p.3 and, Name suppressed, Submission no. 33, p.6

²³³ WHO, *Cancer pain relief and palliative care in children*, 1998, Geneva, available at <http://apps.who.int/iris/bitstream/10665/42001/1/9241545127.pdf>. Note that the WHO advice about treatment of pain in children has been updated in: WHO, *Guidelines on pharmacological treatment of persisting pain in children with medical illnesses*, 2012, Geneva, available at http://whqlibdoc.who.int/publications/2012/9789241548120_Guidelines.pdf

The care needs of children and adolescents with conditions such as cystic fibrosis or multiple sclerosis will also vary significantly during the course of their life and may include periods of more intense medical intervention.

8.2 Level of need for palliative care

The PPCS at the Royal Children’s Hospital estimates that approximately 50 children die each year from a life-limiting condition. Overall, there are approximately 1,200 children in Queensland with a life-limiting condition (defined as a condition where the child is likely to die before the age of 18 years) and it is estimated that at least half will need access to palliative care.²³⁵ The potential number of young palliative patients is relatively small compared to adults; however, as noted above, their different needs affect the capacity of services to meet needs. It is generally recognised that adult palliative care services may not be well equipped to meet the needs of children and adolescents.

The lack of a critical mass of child and adolescent patients also has an impact on service delivery. For example, the Western Australian “Paediatric and Adolescent Palliative Care Model of Care” notes that the relatively small number of patients and the geography of the state affect economies of scale. It also means that health professionals may encounter children and adolescents with palliative care needs infrequently.²³⁶ This in turn limits health professionals’ capacity to develop and maintain expertise in children and adolescent palliative care. Elsewhere in this report the committee has recommended that all HHS have clear arrangements for consultation and liaison with specialist palliative care services (see Chapter 13), including consultation with the specialist PPCS.

8.3 Information and access to services

A number of submissions raised concerns about a lack of clear information about services, and the lack of co-ordination between services. The parents of a child with a life-limiting condition stated that access to services largely depends on the ability of the parent to advocate and their level of education and cultural heritage.²³⁷ They expressed concerns that, currently, parents must spend precious time advocating, finding and organising services, equipment and funding. They noted that there is no central point of referral on diagnosis nor is there any case management.²³⁸ Those concerns were echoed by another parent who described how they identified relevant service providers, contacted each one and then co-ordinated the available support services. In addition to the shock of their child’s diagnosis, caring for a newborn and the usual time pressures of work, home and family, arranging and coordinating support services was very difficult and took time that they would rather have spent with their child.²³⁹

One submission suggested that it is essential that information is provided to parents at the point of diagnosis. A ‘cohesive strategy’ is needed to ensure that consistent information is available from government and non-government organisations to inform parents (and service providers) about services and entitlements.²⁴⁰ Another submitter suggested that on-line information resources and a moderated peer support forum for parents would be an effective way to provide information and support for time-poor parents.²⁴¹

²³⁴ Association for Children’s Palliative Care, *A guide to the development of children’s palliative care services*, 2009, ACT (Association for Children’s Palliative Care), Bristol, United Kingdom

²³⁵ Queensland Kids, Submission no. 32, p.4

²³⁶ Western Australia Cancer and Palliative Care Network, *Paediatric and Adolescent Palliative Care Model of Care*, September 2009, p.19, available at http://www.healthnetworks.health.wa.gov.au/modelsofcare/docs/Paediatric_Adolescent_Palliative_Care_MOC.pdf

²³⁷ Fiona Engwirda, Submission no. 70, p.12

²³⁸ Fiona Engwirda, *ibid.*, p.9

²³⁹ Brett and Louise Carter, Submission no. 30, p.3

²⁴⁰ Fiona Engwirda, *ibid.*, pp.12 & 13

²⁴¹ Name suppressed, Submission no. 33, p.5

Queensland Health acknowledged that it can be difficult for families to negotiate the health system, and that a child often needs services from multiple agencies. Ensuring care is coordinated between multiple service providers is challenging. The Mater has a Complex Care Service and the Royal Children's Hospital has the PPCS (which as noted in section 4.7 provides direct care and a consulting service to other health and care providers), however not all needs can be met, and care differs for children who are not referred to these services.²⁴²

The Department of Communities, Child Safety and Disability Services advised that people seeking Queensland Community Care Services can contact a local service provider, or a regional Community Access Point for "entry, intake, assessment, and referral" services. The Community Access Points can also be contacted through a central telephone service.²⁴³ Ozcare and Blue Care were chosen by the Department of Communities, Child Safety and Disability Services to provide Community Access Points as an interim arrangement for 2012–13. The service model is to be reviewed to inform future directions.²⁴⁴

8.3.1 *Co-ordination and case management*

Three submissions suggested that a specialised case worker or advocacy assistance be provided for families to assist with information about, and co-ordination of, care at what is a highly stressful time.²⁴⁵ The committee notes that some families of children who need palliative care are often also clients of the Department of Communities, Child Safety and Disability Services (Department of CCSDS), and receive services either through Queensland Community Care Services or Specialist Disability Services. One family was advised that their child's medical needs were "too medically complex" to receive disability services from the Department of CCSDS.²⁴⁶

Service co-ordination issues that were raised about children and adolescent palliative care also apply to adults, and are discussed further in Chapter 23.

8.3.2 *Awareness of children's palliative care needs among health providers*

Access to palliative care services can also be affected by the level of awareness and understanding of palliative care among health providers. CanTeen stated that some parents were not aware of palliative care services until the day their child passed away.²⁴⁷

One parent of a child with a life limiting illness explained that they became aware of the specialist PPCS from other families, rather than from medical specialists or others in their child's health care team. The parent requested a referral to PPCS. The child's medical specialists were not aware that the child was eligible for palliative care, as they thought that palliative care services were only for the final stages of life.²⁴⁸ In this instance, referral to palliative care led to significant improvements in the child's quality of life through the management of pain.

This experience points to the importance of ensuring that health providers are supported with better information and knowledge about palliative care, which is discussed in Chapter 14. It also highlights the importance of good information services and collaboration and co-ordination between government departments and services, which is discussed further in Chapter 23.

²⁴² Queensland Health, Submission no. 35, pp.12 & 13

²⁴³ DCCSDS, Submission no. 76, p.8

²⁴⁴ DCCSDS, *Frequently Asked Questions – Assessment and Referral*, accessed 21 March 2013 from <http://www.communities.qld.gov.au/resources/disability/faq-assessment-referral.pdf>

²⁴⁵ Brett and Louise Carter, Submission no. 30, Queensland Kids, Submission no. 32 and Nicole Lipp, Submission no. 53

²⁴⁶ Name suppressed, Submission no. 33, p.3

²⁴⁷ CanTeen, Submission no. 36, p.3

²⁴⁸ Name suppressed, Submission no. 33, p.5

8.4 Specialist paediatric palliative care consultation and advice

Because of children's specific palliative care needs, and the relatively small number of children affected, most health professionals are not in a position to develop the depth of expertise required for high quality care. Access to a specialist paediatric palliative care consultation service to obtain advice is therefore particularly important, so that patients can be cared for by other health professionals with input from specialists when required.

The Queensland Clinical Senate pointed to constraints in the capacity of the existing PPCS in its suggestions that a 24-hour state-wide telephone support service for non-cancer patients should be developed, and service provision in regional areas should be enhanced. The Clinical Senate recommended that key staff positions of staff specialist, nurse practitioner and bereavement co-ordinator should be doubled.²⁴⁹

The committee considers that adequate resourcing of the PPCS is important to ensuring that palliative care for children and adolescents can be provided, to the greatest extent possible, by local health and care providers, supported by a specialist palliative care consultation service. The committee's recommendations about resourcing of palliative care services are in Chapter 18.

8.5 Palliative care for adolescents

CanTeen stated that adolescents as young as 15 are currently being treated in adult oncology services at Queensland Health. This can be very isolating for an adolescent who is away from their peers – not just because they are around no one who is in a similar age range, but also because they are around people who have lived and are ready to die. CanTeen also stated that young oncology patients aged 18 and beyond are treated in a paediatric hospital, which causes similar problems of isolation for teenagers who are unable to relate to their peers. Both options fail to provide an adequate environment.²⁵⁰ Young Care and the Queensland Nurses Union agreed that it is inappropriate for children or adolescents to be cared for in an adult hospice environment.²⁵¹ The committee understands that St Vincent's Hospital Brisbane intends to establish a palliative care service for 14 to 18 year old adolescents. However, this service will initially be only available to patients with private health insurance.²⁵²

8.6 Bereavement support and counselling

Submissions stated that bereavement support for a child, their siblings and other family and friends is particularly important in child and adolescent palliative care. Grief and loss counselling and bereavement support is an important component of paediatric palliative care and requires specific expertise. Without appropriate support there is a risk of complicated grief and prolonged bereavement of family members, including siblings.²⁵³

Six submissions stated that access to bereavement and counselling services is not adequate.²⁵⁴ Ms Kerri-Anne Dooley, Vice-President, Palliative Care Queensland, stated that "... we recently saw the closure of a significant service out of St Vincent's in Brisbane due to funding and that has created huge gaps in services now where families are unable to access free services for bereavement and counselling".²⁵⁵ Two submissions from parents of children with a life-limiting condition described

²⁴⁹ Queensland Clinical Senate, Submission no. 63, p.2

²⁵⁰ CanTeen, *ibid.*, pp.2 & 5

²⁵¹ Youngcare, Submission no.10, p.1 and Queensland Nurses Union, Submission no. 66, p.3

²⁵² St Vincent's Hospital Brisbane, Submission no. 44, p.7

²⁵³ Himelstein BP, 'Palliative care for infants, children, adolescents, and their families', *Journal of Palliative Medicine*, 2006, Vol.9, No.1, pp.163–81

²⁵⁴ Wesley Mission Brisbane, Submission no. 26; Brett and Louise Carter, *ibid.*; Queensland Kids, *ibid.*; CanTeen, *ibid.*; Name suppressed, Submission no. 42 and PCQ, Submission no. 74

²⁵⁵ Kerri-Anne Dooley, Vice President, Palliative Care Queensland, *Public Hearing Transcript*, 22 August 2012, p.7

how after their child died, services stopped. They had no bereavement support.²⁵⁶ One submission highlighted Bear Cottage in Sydney as an example of a service which ensures that follow-up grief and counselling support is provided to families. Such a service could also assist families with funeral arrangements.²⁵⁷

Queensland Health acknowledged that support for bereavement has been identified as an area for further development, and growth in services is needed. Queensland Health also acknowledged that there are minimal supports and services for bereaved siblings.²⁵⁸

8.7 Hospice and respite care

Currently, there are only two paediatric hospices in Australia: ‘Bear Cottage’ in Sydney and ‘Very Special Kids House’ in Melbourne. Both hospices provide end of life residential care and respite care. Australia’s small number of paediatric hospices contrasts with the United Kingdom which has 44 children’s hospices and a population of 63 million. With a population of approximately 23 million, Australia would need 16 paediatric hospices to provide a similar ratio of services, three of which would be in Queensland.²⁵⁹ As there are no equivalent services in Queensland, some families travel interstate to access these services. The committee heard that over the last 12 months, six families from Queensland went to Bear Cottage.²⁶⁰

The committee heard from Mr and Mrs Quilliam who established “Queensland Kids” to advocate for the establishment of a children’s hospice, Hummingbird House, to provide respite and hospice care, after-hours support, education and information about palliative care and services to families as well as transition pathways from hospital treatment to palliative care.²⁶¹ The proposal for a dedicated residential children’s hospice in Queensland was supported by 15 submissions.²⁶²

The Queensland Kids proposal is for a hospice to support dying children and their families and to provide respite services for children with a life-limiting illness, and sibling support and bereavement services.²⁶³ Queensland Kids estimated the operational costs for a hospice would be similar to Very Special Kids House in Victoria, which costs over \$1.5 million to operate the facility, from a total of \$4.5 million as their organisational budget.²⁶⁴ The committee notes that the Victorian government contributes 34 per cent of the annual operating cost of Very Special Kids House.²⁶⁵ Queensland Kids believes there is scope for recurrent government funding, however, it considers that a children’s hospice should be supported by non-government organisations and community input.²⁶⁶

One submission from a parent of a child with a life-limiting condition encapsulated the views expressed in many submissions on this issue. The submitter advocated strongly the need for a children’s palliative care service to provide children with the choice to die in a supportive, non-hospital environment. The submitter stated the service should include a central advisory service for parents that can refer to specialists, counselling and support agencies, and provide advice on

²⁵⁶ Tracy and Warren Taprell, Submission no. 28, p.3 and Nicole Lipp, Submission no. 53, p.6

²⁵⁷ Fiona Engwirda, *ibid.*, p.11

²⁵⁸ Queensland Health, Submission no. 35, p.12

²⁵⁹ Paul Quilliam, *Public Hearing Transcript*, 22 August 2012, p.16

²⁶⁰ Gabrielle Quilliam, Co-founder, Queensland Kids, *Public Hearing Transcript*, 22 August 2012, p.18

²⁶¹ Queensland Kids, Submission no. 32, pp.7, 12 & 17

²⁶² Jennie Martin, Submission no. 3; Brett and Louise Carter, Submission no. 30; Queensland Kids, *ibid.*; Name suppressed, Submission no. 33; CanTeen, Submission no. 36; Regina Miller, Submission no.41; Name suppressed, Submission no. 42; St Vincent’s Hospital Brisbane, Submission no. 44; Nicole Lipp, *ibid.*; National Disability Services, Submission no. 54; Tiffany and Malcolm Heddes, Submission no.56; Queensland Nurses Union, Submission no.66; Fiona Engwirda, *ibid.*; Anglicare Southern Queensland, Submission no. 72 and PCQ, Submission no. 74

²⁶³ Gabrielle Quilliam, *ibid.*, p.18

²⁶⁴ Paul Quilliam, *ibid.*, 22 August 2012, p.17

²⁶⁵ Very Special Kids, *Commonly asked questions and answers about Very Special Kids House*, accessed 26 February 2013 from www.vsk.org.au/our-services/very-special-kids-house

²⁶⁶ Gabrielle Quilliam, *ibid.*, p.18

medications, advocacy, death and funeral planning. It should also incorporate a hospice/respite facility and educate doctors and nurses in children's palliative care.²⁶⁷ One submission stated that a lack of a children's hospice contributes to carer burnout and unnecessary hospital admissions.²⁶⁸

The committee considers that there is a clear need for hospice care for children and adolescents and their families. Based on the models of care in other jurisdictions, the committee recommends that the establishment of a service by a non-government organisation is desirable. It is critically important that, when established, a hospice have strong linkages with the specialist paediatric palliative care service operated by the Children's Health Queensland HHS.

Recommendation 3 – Children's hospice

The committee recommends that the Minister for Health work with the Commonwealth Minister for Health to provide a children's hospice in Queensland, with strong links with the specialist Paediatric Palliative Care Service at the Children's Health Hospital and Health Service. The hospice should provide end-of-life care, respite care for children and adolescents with a life-limiting condition, information and advice on accessing services and bereavement counselling and support for families, including siblings.

²⁶⁷ Nicole Lipp, *ibid.*, pp.1 & 5
²⁶⁸ PCQ, *ibid.*, p.10

Chapter 9. Aboriginal and Torres Strait Islander people – accessible and appropriate palliative care

*Know where someone comes from.*²⁶⁹

9.1 Level of need for palliative care

Aboriginal and Torres Strait Islander Australians are more likely than other Australians to suffer chronic health conditions such as end-stage kidney disease and diabetes.²⁷⁰ For example, in 2007–2008, Aboriginal and Torres Strait Islander people started dialysis or kidney transplant at eight times the rate of others,²⁷¹ and in 2004–2008, Aboriginal and Torres Strait Islander people died from diabetes at seven times the rate of other Australians.²⁷² As noted in Chapter 7, those people expected to benefit from palliative care are increasingly people with chronic disease rather than people with cancer.

Life expectancy for Aboriginal and Torres Strait Islander people is considerably shorter than for other Australians. Estimates of life expectancy of Aboriginal and Torres Strait Islander males is 11.5 years less than for other males, and Aboriginal and Torres Strait Islander females are expected to live 9.7 years less than other Australian females.²⁷³ Medicare spending per person in 2010–11 was substantially lower for Aboriginal and Torres Strait Islander people at \$493 than for other Australians at \$737.²⁷⁴

A high level of need for palliative care services is reflected in the number of Aboriginal and Torres Strait Islander people admitted to hospital for palliative care. In Australia in 2009–2010, there were 812 palliative care hospital separations²⁷⁵ for Aboriginal and Torres Strait Islander people. This was one and a half times higher per 10,000 population for Aboriginal and Torres Strait Islander people than for other Australians. A similar pattern is observable for all public hospital separations.²⁷⁶

While there is a high rate of chronic disease, and consequent need for palliative care, the available data indicates that Aboriginal and Torres Strait Islander people are significantly less likely to have been diagnosed with cancer than other Australians in the five year period from 2003 to 2007.²⁷⁷ The relatively low diagnosis rate may be explained by Aboriginal and Torres Strait Islander people accessing medical care less than the rest of the population. The death rate for all cancers in 2006–07 was 26 per cent higher for Aboriginal and Torres Strait Islander Queenslanders than for others, suggesting that they may not be benefiting from early diagnosis and effective treatment.²⁷⁸

Generally, Aboriginal and Torres Strait Islander people have a relatively high level of need for palliative care at a younger age. This, coupled with cultural requirements and remoteness, places unique demands on the provision of palliative care services. A significant proportion (25 per cent) of

²⁶⁹ Dr Marjad Page, Mount Isa Hospital, document tabled at public hearing of 4 February 2013, Mount Isa, p.7, available at <http://www.parliament.qld.gov.au/documents/committees/HCS/2012/PalCareHAAC/tp-4Feb2013-page.pdf>

²⁷⁰ AIHW, *Trends in palliative care in Australian Hospitals*, p.19

²⁷¹ AIHW, *Australia's Health 2012*, p.327

²⁷² AIHW, *ibid.*, p.305

²⁷³ AIHW, *Trends in palliative care in Australian Hospitals*, p.19

²⁷⁴ AIHW, *Expenditure on health for Aboriginal and Torres Strait Islander people 2010–11*, 2013, Canberra, p.11, available at <http://www.aihw.gov.au/publication-detail/?id=60129542787>

²⁷⁵ Separation is the end of an episode of care, see glossary.

²⁷⁶ AIHW, *Palliative care services in Australia 2012*, p.16

²⁷⁷ AIHW, *Trends in palliative care in Australian Hospitals*, p.19

²⁷⁸ Queensland Health, *The Health of Queenslanders 2012: Advancing good health*, Fourth report of the Chief Health Officer Queensland, 2012, p.30, available at http://www.health.qld.gov.au/cho_report/2012/documents/2012-cho-report-all.pdf

Aboriginal and Torres Strait Islander people live in rural and remote areas of Australia, compared with 2 per cent of other people.²⁷⁹

The Queensland Aboriginal and Islander Health Council reports that in 2011, the Queensland Aboriginal and Torres Strait Islander population aged 45 years and older was 28,504. In the same year 9,036 of those individuals (31.7 per cent) accessed Aboriginal and Islander Community Controlled Health Services.²⁸⁰

Evidence provided to the committee in submissions and by witnesses identified the following gaps in the delivery of palliative care services to Aboriginal and Torres Strait Islander people: the capacity and cultural awareness of health and care providers; the small number and capacity of Aboriginal and Torres Strait Islander health and care providers; access to culturally appropriate accommodation; and a lack of awareness amongst Aboriginal and Torres Strait Islander people about palliative care.

9.2 Culturally appropriate palliative care

The importance of providing culturally safe and appropriate palliative care services to Aboriginal and Torres Strait Islander people was raised with the committee. Submissions and witnesses stated that care and health workers need to be particularly aware of Aboriginal and Torres Strait Islander people's views about death, the important role of the community and Elders, and the spiritual connection to home and country. Some people may fear and mistrust hospitals and Western medicine. The COTA, Queensland stated that the perception that a service did not provide culturally appropriate assessment or services was sufficient to deter many Aboriginal and Torres Strait Islander patients from approaching palliative care services.²⁸¹

Pam McGrath and Hamish Holewa's study of an Aboriginal community in the Northern Territory identified the following eight principles which should underpin the delivery of palliative care services to Indigenous people:

- **Cultural safety** – based on a respect for Indigenous culture as understood and expressed by Indigenous people
- **Equity** – democratic right of equal access to services. One of chief obstacles is seen to be the concentration of most palliative care services in towns and urban areas
- **Autonomy** – people's right to make fundamental choices, with the family, and health care professionals' task being to implement and support those wishes. Important to note that the notion of choice for an Indigenous patient is not individualistic as with Western culture, but is based on family and community relationships
- **Importance of trust** – Indigenous people place great emphasis on relationships. Providers therefore need to establish and build relationships with families over long term
- **Humane, non-judgmental care** – part of the job description of health professionals is to provide compassion to sick individuals with an accepting attitude
- **Seamless care** – the collaboration of the multi-disciplinary mix of health professionals on a continuum of care for the patient and their family
- **Emphasis on living** – quality of life with emphasis on the living rather than the dying, and
- **Respect** – notion of respect to permeate all dealings with Indigenous peoples.²⁸²

Similar guiding principles have been identified by Queensland Health in guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying. The four guiding principles for

²⁷⁹ AIHW, *ibid.*, p.19

²⁸⁰ Queensland Aboriginal and Islander Health Council, Submission no. 60, p.1

²⁸¹ Council on the Ageing – Queensland (COTA), Submission no. 48, p.3

²⁸² McGrath P and Holewa H, *The Living Model – a resource manual for Indigenous palliative care service delivery*, 2006, Researchman Australia, Toowong, Qld, pp.17–20

care for Aboriginal and Torres Strait Islander people and their family, faced with death are: cultural respect and recognition; communication; relationships and partnerships; and capacity building.²⁸³

The committee notes that cultural practices and needs vary considerably between different Aboriginal and Torres Strait Islander peoples, and between people with varying connections to their culture and tradition. Cultural issues and the awareness of health and care providers that were brought to the committee's attention include:

- the centrality of the family, rather than the individual, and the importance of 'skinship and kinship'²⁸⁴ structures
- the importance of building good relationships with community leaders, Elders, older people, and the respected people in the community²⁸⁵
- differing interpretations of death and dying, and of hospital. For example, some people may see hospital as a place one goes to die, rather than a place to heal or fix health problems²⁸⁶
- the importance some Aboriginal and Torres Strait Islander people place on dying at home, in their own country, and
- the importance of health and care providers using easily understood and culturally appropriate language.²⁸⁷

9.3 Improving capacity to deliver culturally appropriate palliative care

9.3.1 Cultural awareness among health and care providers

The committee heard evidence that there is a lot to be done to improve the cultural awareness and capacity of care and health workers who work with Aboriginal and Torres Strait Islander people, especially knowledge of local Indigenous groups. Kincares' submission suggested that mainstream palliative care services may not provide culturally appropriate care due to a lack of understanding of Indigenous culture, rigidity in systems, and a lack of training of staff in cultural competencies and person-centred care.²⁸⁸ Mrs Mona Phillips, an Indigenous Nurse Support Officer, told the committee that there is not "... enough understanding or training out there provided to health professionals to understand Indigenous health a lot more in depth".²⁸⁹ Palliative Care Queensland recommended that specific Aboriginal and Torres Strait Islander cultural awareness education and training should be made mandatory for all providers of end of life care.²⁹⁰

9.3.2 Existing initiatives to improve cultural awareness of health and care providers

A number of resources and initiatives are available to promote improved cultural awareness of health and care providers. For example, improving the cultural capability of health workers through a cultural capability learning program is an element of the Queensland Health *Aboriginal and Torres*

²⁸³ Queensland Health, *Sad News, Sorry Business – Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying*, Ver. 1, 2011, Brisbane, p.5, available at http://www.health.qld.gov.au/atsihealth/documents/sorry_business.pdf

²⁸⁴ Dr Marjad Page, Mount Isa Hospital, *Public Hearing Transcript*, 4 February 2013, p.19. 'Skin' group or 'skinship' refers to a person's group under often complex social arrangements which establish a person's place in their traditional group, and regulates social relations such as marriage. There are other traditional social classifications, e.g. moiety system. (Australian Institute of Judicial Education, *Equality before the Law Bench Book*, Section 2 'Indigenous people', accessed 24 April 2013 from <http://aija.org.au/Aboriginal%20Benchbook%202nd%20Ed/Chapter%202.pdf>

²⁸⁵ Dr Marjad Page, *ibid.*, pp.10, 11 & 13

²⁸⁶ Queensland Health, *Sad News, Sorry Business*, p.6

²⁸⁷ Dr Marjad Page, *ibid.*, pp.10–11

²⁸⁸ Kincares, Submission no. 39, pp.5–6

²⁸⁹ Mona Phillips, Indigenous Nurse Support Officer, Mount Isa Centre for Rural and Remote Health, *Public Hearing Transcript*, 4 February 2013, p.20

²⁹⁰ PCQ, Submission no. 74, p.37

Strait Islander Cultural Capability Framework 2010–2033.²⁹¹ Queensland Health has published guidelines on its website, *Sad News, Sorry Business – Guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying*,²⁹² which describes a range of issues to consider when caring for Aboriginal and Torres Strait Islander patients, including communication and language issues. Pam McGrath provided the committee with a copy of *The Living Model – a resource manual for Indigenous palliative care service delivery*,²⁹³ and the Department of Health and Ageing has published a resource kit which aims to support training in mainstream health services.²⁹⁴

Brisbane South Palliative Care Collaborative, a partnership between Metro South Palliative Care Services, Metro South Hospital and Health Service and Griffith University School of Medicine has developed introductory workshops, “A Palliative Approach for Staff in Aboriginal and Torres Strait Islander Aged Care Services” which is funded by Palliative Care Australia.²⁹⁵

There are many other documents, training materials and course designs available to support improving cultural awareness and understanding. An Aboriginal health worker suggested that encouraging Aboriginal or Torres Strait Islander people to be members of Hospital and Health Boards could help to address some health issues that affect those communities.²⁹⁶

Recommendation 4 – Aboriginal and Torres Strait Islander cultural training

The committee recommends that the Minister for Health ensure that service agreements, purchasing arrangements and funding for Hospital and Health Services which provide palliative care encourage the provision of targeted training in Aboriginal and Torres Strait Islander cultural issues and perspectives for staff who provide palliative care services.

9.3.3 Person-centred care and place of death

The committee strongly supports the concept of person-centred care that facilitates patient choice to the extent possible, and this is discussed in several sections of this report. For Aboriginal and Torres Strait Islander people, preferences about where to spend one’s final days are likely to be as diverse as in other parts of the Australian population. Often people prefer to be at home initially. “Then it is up to the family. Sometimes our Aboriginal people do not want their loved one to die at home and other times they do. It depends entirely on the family and the patient.”²⁹⁷

Indigenous people from remote areas who leave their country to receive palliative care may face difficulties if they wish to return home to die. The committee heard moving stories of Aboriginal and Torres Strait Islander people who had relocated in order to receive treatment and palliative care, who wanted to return home, but died away from family and country.

Financial assistance for travel and accommodation is available to patients under the Queensland Government’s Patient Travel Subsidy Scheme (PTSS). However, there appears to be a lack of understanding or awareness of the scheme, particularly in relation to end of life care. The PTSS

²⁹¹ Queensland Health, *Aboriginal and Torres Strait Islander Cultural Capability Framework 2010–2033*, accessed 26 March 2013 from http://www.health.qld.gov.au/atsihealth/documents/cultural_capability.pdf,

²⁹² Queensland Health, *Sad News, Sorry Business*

²⁹³ McGrath and Holewa, *The Living Model – a resource manual for Indigenous palliative care service delivery*

²⁹⁴ DOHA, *Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples: Resource Kit*, accessed 26 March 2013 from www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-indig-resource.htm

²⁹⁵ Professor Liz Reymond, Submission no. 11, p.5

²⁹⁶ Mona Phillips, *Public Hearing Transcript*, 4 February 2013, p.21

²⁹⁷ Diana Ross, Townsville Aboriginal and Torres Strait Islander Health Service, *Private Roundtable Discussion Transcript*, 5 February 2013, p.2

subsidises the cost of travel and accommodation for a patient who is required to travel more than 50 kilometres from their closest public hospital to obtain a specialist service elsewhere. If, for example, a patient relocated from a remote area to a regional centre for regular dialysis, and wished to return home to die, the PTSS would be available for the return journey.

If a patient dies at a location they have been required to travel to for treatment, for example for palliative care, a relative may receive a subsidy equivalent to a full economy fare to the nearest airport to the deceased person's normal place of residence. This subsidy can be used to transport the deceased person's body back to the location of the hospital nearest to the deceased's normal place of residence.²⁹⁸ Any additional costs of transporting a person's body to their home are not covered by the PTSS.

It was apparent from information given to the committee that stakeholders were not aware that the PTSS could be available to support people who chose to return home near the end of life, and to assist with the costs associated with returning a person's body home. The committee recommends that information be made available to public sector palliative care services and to Aboriginal and Torres Strait Islander health services about the application of the PTSS to these palliative care situations.

Recommendation 5 – Promote awareness of Patient Travel Subsidy Scheme

The Minister for Health ensure that palliative care services and Aboriginal and Torres Strait Islander Health Services are made aware of the Patient Travel Subsidy Scheme and the situations in which financial assistance may be available to palliative patients and their families.

9.3.4 Appropriate accommodation and space for family during palliative care

When people from rural or remote areas relocate to a larger centre for palliative care (whether inpatient or outpatient) suitable accommodation for the patient and their family may be difficult to access. Dr Don Bowley stated that while some Aboriginal organisations have subsidised accommodation in Mount Isa, for example, Kabalulumana Hostel, there are still challenges because often it is full. In those circumstances, relatively expensive motels are the alternative.²⁹⁹

Dr Tina Andrews highlighted the need for appropriate places for family members and friends who visit inpatients. Dr Andrews explained that "Indigenous people feel very uncomfortable with going ... [to a hospital ward] to visit their own. The wailing and crying is all part of the grieving process. They are having to stifle that. They cannot do it because everything is too cramped."³⁰⁰

Dr Marjad Page highlighted practical issues associated with providing culturally appropriate palliative care in hospital, so that people's needs to conduct smoking ceremonies, sorry business and family business. Dr Page described trying to conduct "... a smoking ceremony in Ipswich (hospital) and everything went off and we did not do anything again. That is disrespectful, especially to the really traditional Aboriginals."³⁰¹

²⁹⁸ Queensland Health, *Patient Travel Subsidy Scheme – Information for patients and their carers*, December 2012, available at <http://www.health.qld.gov.au/ptss/docs/Patients-Guide.pdf>

²⁹⁹ Dr Don Bowley, Royal Flying Doctor Service, *Private Roundtable Discussion Transcript*, 4 February 2013, p.5

³⁰⁰ Mary Cotterell, Palliative Care/Aboriginal Liaison Officer, Mount Isa Hospital, *Public Hearing Transcript*, 4 February 2013, p.10

³⁰¹ Dr Marjad Page, *Public Hearing Transcript*, 4 February 2013, p.7

Recommendation 6 – Accommodation for Aboriginal and Torres Strait Islander people

The Minister for Health consider how accommodation for Aboriginal and Torres Strait Islander patients and their family and friends can be best provided during periods when patients are away from their usual residence to receive palliative care or other related treatment.

9.4 Aboriginal or Torres Strait Islander health and care providers

In its *A blueprint for action – Pathways into the health workforce for Aboriginal and Torres Strait Islander people*, the National Aboriginal and Torres Strait Islander Health Council stated that a key way to provide culturally safe services that meet the needs of Aboriginal and Torres Strait Islander people was to increase the number and capacity of Aboriginal and Torres Strait Islander people working in the health workforce.³⁰²

This view was reflected in submissions and by witnesses. For instance, Dr McGahan highlighted the benefits of employing staff with an Aboriginal background in general practice. He explained that a barrier to the population accessing general practice is the perception that they are not welcome. If an Aboriginal or Torres Strait Islander person is employed this perception evaporates.³⁰³

Other evidence to the committee indicated that there are insufficient Aboriginal and Torres Strait Islander health and care providers.³⁰⁴ This is discussed in Chapter 14 *Workforce capacity*.

9.4.1 Promoting awareness of palliative care services

The committee heard that work is needed to promote awareness of palliative care among Aboriginal and Torres Strait Islander people. This is discussed in Chapter 16 of this report.

³⁰² National Aboriginal and Torres Strait Islander Health Council, *A blueprint for action – Pathways into the health workforce for Aboriginal and Torres Strait Islander people – Executive summary*, 2008, p.2, available at <http://www.limenetwork.net.au/files/lime/Blueprint%20for%20action.pdf>

³⁰³ Dr McGahan, Private capacity, *Public Hearing Transcript*, 5 February 2013, p.12

³⁰⁴ Mona Phillips, *Public Hearing Transcript*, 4 February 2013, p.20

Chapter 10. Other cultural, language and lifestyle groups – accessible and appropriate palliative care

10.1 Cultural and language groups

In Australia, over 300 languages are spoken, more than 100 religions and beliefs are practised and many of the world's ethnic groups are represented from over 230 different countries.³⁰⁵ In 2010, 27 per cent of the Australian population was born overseas – nine per cent in mainly English speaking countries (the United Kingdom, Ireland, New Zealand, Canada, the United States and South Africa) and 18 per cent in other countries where English may not be the first language. In 2011, people born in the United Kingdom continued to be the largest group of overseas-born residents (5.3 per cent of Australia's total population), followed by those born in New Zealand (2.5 per cent). A significant percentage of Australia's overseas-born residents were born in countries where English is not the first language – China (1.8 per cent), India (1.5 per cent) and Vietnam and Italy (0.9 per cent).³⁰⁶ Australia's ageing culturally and linguistically diverse population is experiencing more rapid growth than the general population.³⁰⁷

10.2 Issues that affect palliative care

Research suggests that differences in beliefs, values and traditional health care practices are of particular relevance at the end of life and that choices made about end-of-life medical treatment decisions may be more related to ethnicity and culture than to age, education, socio-economic status, or other variables.³⁰⁸ Cultural factors shape patient preferences around decision making, receiving bad news and end of life care. For example, the Western developed world's emphasis on patient autonomy, informed consent and truth telling is often at odds with the belief and values of some cultural groups who may place greater value on family involvement in decision making. Discussing death is also actively discouraged in some cultures.³⁰⁹

It is not uncommon to offer people the opportunity to die at home. For some people this may not be preferred. Death in the home may dictate the need for elaborate cleansing rituals, or may mean the house is abandoned. In other cultures, it will be important for religious or spiritual practitioners to attend the dying person.³¹⁰

Ensuring that people have equitable care at the end of life therefore requires an awareness and commitment to deliver culturally appropriate palliative care. Delivering culturally appropriate care should also be founded on mutual trust, respect of the patient's nationality, culture, age, gender and political and religious beliefs.³¹¹ Submissions noted the importance of taking account of cultural differences when providing palliative care services.³¹² The Council on the Ageing, Queensland said that a perception that a service did not provide culturally appropriate services was sufficient to deter many patients from approaching those services for support.³¹³

³⁰⁵ PCA, *Palliative Care and Culturally and Linguistically Diverse Communities*, accessed 21 March 2013 from <http://www.palliativecare.org.au/Portals/46/Policy/PCA%20Culturally%20and%20Linguistically%20Diverse%20Communities%20and%20Palliative%20Care%20Position%20Statement.pdf>

³⁰⁶ Australian Bureau of Statistics (ABS), *Australia's population by country of birth*, accessed 14 March 2013 from <http://www.abs.gov.au/ausstats/abs@.nsf/Products/84074889D69E738CCA257A5A00120A69>

³⁰⁷ Aleksandric V, 'Partnerships in palliative care: achieving better outcomes for CALD communities', *Australian Mosaic*, No. 22, June 2009, No. 22, pp.47–9

³⁰⁸ Aleksandric V, *ibid.*, p.47

³⁰⁹ Clark K and Phillips J, 'End of life care – the importance of culture and ethnicity', *Australian Family Physician*, April 2012, Vol.38, No 4, pp.2–3

³¹⁰ Clark and Phillips, *ibid.*, p.3

³¹¹ Clark and Phillips, *ibid.*, p.2

³¹² Rev. Dr Ian Mavor OAM FACE, Submission no. 50 and Corina Woodland, Submission no. 6, p.90

³¹³ COTA, Submission no. 48, p.3

Kincare stated that cultural and religious attitudes to life, death and health care will influence the degree to which palliative approaches and specialist palliative care are understood and accepted within culturally and linguistically diverse (CALD) communities. They noted that access to bilingual specialists and palliative care staff is limited, making access to information on services available, diagnostic conditions and disease trajectories harder to access for individuals and families.³¹⁴

The Senate Inquiry noted that people from other cultural and linguistic backgrounds can face additional barriers in accessing care due to lower levels of awareness, linguistic barriers, cultural differences and lack of appropriate services.³¹⁵ To address those barriers, Palliative Care Australia has suggested:

- the adoption of initiatives that build the cultural awareness and cultural competence of the broad health care workforce
- flexibility in models of end-of-life care to accommodate the care preferences of people from culturally and linguistically diverse backgrounds
- training, funding and resourcing of cultural liaison officers with the necessary skills, experience and knowledge
- resourcing and using community consultation to ensure local palliative care services clearly understand the needs of the communities they serve and develop appropriate strategies to meet those needs
- the availability of and support for qualified and trained translators and medical interpreters
- commitment to community capacity building about palliative care through the provision of health information in a range of community languages and targeted health promotion programs to promote access, and
- research in the Australian context of the cultural implications for quality palliative care.³¹⁶

The committee received evidence about those issues, and in particular gaps were identified in: health worker awareness of cultural differences; the provision of training and education; access to interpreters and information in different languages; and access to culturally appropriate services in rural and remote areas.

10.3 Improving capacity to deliver culturally appropriate care

10.3.1 Person-centred care

Consistent with one of the key themes of this report, the capacity to deliver culturally appropriate care will be improved if the approach to care is person-centred. Person-centred care for people from different cultural and language backgrounds requires an understanding of the patient's and family's values and needs. This in turn requires health and care providers with adequate awareness and understanding of cultural issues in palliative care, access to interpreters, and appropriate public education about palliative care and dying. In the Australian palliative care context, being culturally appropriate requires an understanding of:

- the patient's disclosure and consent preferences
- the degree to which individual versus family decision making is preferred
- specific privacy issues
- the meaning assigned to the disease and its symptoms, and
- the patient and their family's attitudes toward medication and nutrition, preferred end of life rituals, and customs and spiritual and/or religious preferences.

³¹⁴ Kincare, Submission no. 39, p.6

³¹⁵ Senate Committee inquiry, *Palliative care in Australia*, p.175

³¹⁶ PCA, *Palliative Care and Culturally and Linguistically Diverse Communities*

Ms Webby, from Blue Care said that person-centred care is significant for people from culturally and linguistically diverse communities. She stated that

*... there are a whole range of issues that, as services, we need to be able to address across the diversity of those different communities. I think if we go back to the concept of a package of care, then that package of care allows people to actually make choices to have the care in the way they need it, which is driven by their cultural background and the range of specific traditions that might exist. That means that services actually need to be responsive to that particular need.*³¹⁷

Taking the time to understand each patient's unique cultural needs, values and beliefs is the most respectful way of delivering palliative care and facilitating a dignified death.³¹⁸ Palliative Care Australia cautioned against taking a 'cookbook' approach where all people from the same culture are treated in the same way, regardless of individual needs and beliefs.³¹⁹ The Australian Medical Association also highlights the importance of recognising that culture-based and religious-based responses may vary within a cultural or religious group.³²⁰

Palliative care should be person-centred, based on needs, and allow patients, families and carers to make choices about their care, including care based on the patient's particular cultural values. The committee considers that palliative care should be delivered in a way that does not discriminate on the basis of a person's cultural background, religion, language or lifestyle. For example, the role of family, relatives and friends in caring for a patient may vary. In some cultures it is not appropriate for a competent patient to make decisions about end of life care.³²¹ For 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.³²²

10.3.2 Training and education in cultural issues affecting palliative care

The importance of incorporating information about cultural issues that affect palliative care into training for specialists and general health and care providers has widespread acceptance, and the committee considers that training should be encouraged. There are emerging issues about cultural understanding and awareness in relation to patients and families from cultural groups that have migrated to Australia relatively recently, and in relation to the workforce in residential aged care facilities.

10.3.3 Recently arrived communities and refugees

There may be additional challenges in providing culturally appropriate care for people from communities that have recently arrived in Australia, including refugees, as health and care providers become familiar with relevant cultural issues. There may be additional challenges in engaging skilled interpreters, particularly for numerically small communities. In addition, refugees who have experienced abuse or torture are likely to have particular needs during treatment and palliative care.

³¹⁷ Glenys Webby, *Public Roundtable Discussion Transcript*, 14 November 2012, pp.12–3

³¹⁸ Clark and Phillips, 'End of life care – the importance of culture and ethnicity', p.3

³¹⁹ PCA, *Palliative Care and Culturally and Linguistically Diverse Communities*

³²⁰ Australian Medical Association, *Position Statement on the Role of the Medical Practitioner in End of Life Care*, 2007, p.3, accessed 26 April 2013 from <https://ama.com.au/position-statement/role-medical-practitioner-end-life-care-2007>

³²¹ Australian Medical Association, *ibid.*

³²² Lienert T, Cartwright C and Beck K, *The Experiences of Gay, Lesbian, Bisexual and Transgender People around End-of-Life Care*, 2010, Southern Cross University, Tweed Heads, NSW, p.48, available at http://www.scu.edu.au/aslarc/download.php?doc_id=11019&site_id=181&file_ext=.pdf. Section 63, *Powers of Attorney Act 1998*, provides that a 'statutory health attorney' is the first, in listed order of the following who is "readily available and culturally appropriate"; a spouse; an adult who has care of the person; or an adult who is a close friend or relation, but not a paid carer. The Act is available at <http://www.legislation.qld.gov.au/LEGISLTN/CURRENT/P/PowersofAttA98.pdf>.

Dr Kastrissios, President, Greater Metro South Brisbane Medicare Local, informed the committee of the

*... problems around our refugee and immigrant populations around language and treating the cultural aspects of a person who is in palliative care and they are from, say, a Somali background. All of these things can be reinforced by and supported by interdisciplinary learning and teaching. That is something that we are struggling to do currently and it is something that we are going to attempt.*³²³

10.3.4 Residential aged care facility staff

Palliative Care Nurses Australia's submission said that "(h)igh numbers of [non-English speaking background] staff in aged care facilities have created issues such as communication and language barriers. Cultural issues around death and dying in this context including differing attitudes to pain management and to the use of opioids."³²⁴ In this context the submission suggested that careful monitoring of the number of staff from non-English speaking backgrounds in residential aged care facilities is important.

In 2012, almost 23 per cent of direct care staff in residential aged care facilities were migrants who spoke a language other than English.³²⁵ The majority (72 per cent) were personal care attendants, who provide direct care to residents, and may be an important source of information to nursing staff and doctors about changes in a palliative resident's condition. To ensure that residential aged care facilities are able to provide quality care with a palliative approach, understanding of cultural differences is important. Karuna Hospice highlighted both the value and the challenge of a high number of staff from other language backgrounds. They suggested that the multi-cultural nature of the staff mix in aged care brings important cultural insights, but that training in cultural issues needs to be accessible to all staff including those from a culturally and linguistically diverse background.³²⁶

The committee considers that education in a palliative approach should be provided for all health professionals working with people at the end life, irrespective of their own cultural background, with an emphasis on cultural issues related to death and dying. In residential aged care, where there are high numbers of staff from a non-English speaking background, training should address different cultural perspectives on palliative care, including pain management. The committee notes that the Australian Government has funded training in palliative care for aged care workers. The main training and professional development schemes are described in Chapter 14 *Workforce capacity*.

Recommendation 7 – Cultural training

The committee recommends that the Minister for Health ensure that service agreements, purchasing arrangements and funding for Hospital and Health Services which provide palliative care encourage the provision of targeted training in cultural issues affecting palliative care for staff who provide palliative care services.

³²³ Dr John Kastrissios, *Public Hearing Transcript*, 22 August 2012, p.22

³²⁴ Palliative Care Nurses Australia Inc., Submission no. 46, p.5

³²⁵ King D, Mavromaras K, Wei Z, *et al.*, *The Aged Care Workforce 2012: Final Report*, 2012, DOHA, Canberra, p.15, available at [http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-nat-agedcare-workforce-census-survey/\\$File/D1010-NACWCAS-Report-Revised.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-nat-agedcare-workforce-census-survey/$File/D1010-NACWCAS-Report-Revised.pdf)

³²⁶ Wesley Mission Brisbane, Submission no. 26, p.5

10.3.5 Interpreters and information

Professor Liz Reymond, Clinical Director, Metro South Palliative Care Services (MSPCS), informed the committee that one of the particular challenges faced by MSPCS, which cares for one of the most culturally and linguistically diverse populations in Queensland, is obtaining appropriate and robust interpreters. Professor Reymond explained that the monetary cost alone of obtaining interpreters is significant.³²⁷ Professor Reymond stated that

*the need for interpreters and the cost of those interpreters and having an interpreter who is resilient enough to handle the conversations. Sometimes they make people culturally feel uncomfortable, both the carers and providers. I agree with you that it is very difficult. I think this is one of the problems with a lack of resources. If we had the resources we could do a lot more.*³²⁸

Recommendation 8 – Needs based funding and interpreters

The committee recommends that the Minister for Health ensures that needs based funding to Hospital and Health Services for palliative care take account of the anticipated cost of interpreters in locations with a high proportion of people who speak a language other than English.

Recommendation 9 – Promote use of interpreters

The committee recommends that the Minister for Health direct Queensland Health to use service agreements and purchasing arrangements to ensure that Hospital and Health Services and non-government organisations that receive public funds use interpreters when needed.

³²⁷ Professor Liz Reymond, Submission no. 11, p.10

³²⁸ Professor Liz Reymond, *Public Roundtable Discussion Transcript*, 14 November 2012, p.12

Chapter 11. Access to palliative care services – regional and rural

*Supporting quality of life for people near the end of their life is an important part of health service provision in rural and remote communities, as it is elsewhere in this country.*³²⁹

11.1 Introduction

A significant proportion of Queenslanders live in the south-east corner of the state and the remainder of the population is widely dispersed. Regional and remote areas vary greatly, from sparsely populated outback and tropical rainforest areas to coastal communities, regional centres and mining towns. On average, people who live in regional and remote areas have shorter lives and higher levels of some illness than people who live in major cities. At June 2011, 69 per cent of the Australian population lived in the major cities and just two per cent in remote or very remote Australia. The remaining 28 per cent lived in inner regional and outer regional areas. In Queensland, three per cent of people live in remote or very remote areas and 36 per cent in regional areas.³³⁰

Rural health care is often associated with higher costs, decreasing numbers of health care providers. Trends toward centralisation of services affect access to health care services for people in rural and remote areas. The health care needs of people in rural and remote areas remain high, particularly in palliative care.³³¹

11.2 Access to palliative care in regional and rural areas

Submissions and witnesses highlighted that access to specialist palliative care services in rural and remote areas is not equitable, and drew attention to some of the challenges in delivering accessible services. Palliative Care Australia said that access and equity are fundamental to palliative care being effective in addressing needs. It noted that in the more rural and remote areas, issues of access to both specialist and generalist palliative care providers, including GPs, are compounded.³³² Clinicians from rural areas noted that there are gaps in services and access is not equitable.³³³

In rural areas, accessing after-hours care can be problematic. For people whose palliative needs are complex, access to specialist palliative care services is often not viable in rural and remote locations, and there are insufficient specialist palliative care physicians available to meet needs.³³⁴ This was reinforced by a regional care provider who commented on the limitations on home care imposed by distance. “Individuals who wish to die at home, may be discouraged due to the distance from help in the event of uncontrolled pain or other symptoms.”³³⁵

Cairns HHS described the limited palliative care services in its area, and noted research about cancer inequalities in cancer care which indicates that the further a cancer patient lives from a metropolitan centre, the more likely they are to die within five years of diagnosis. Factors which contribute to this include geographic isolation, transport issues, and a high proportion of disadvantaged population

³²⁹ National Rural Health Alliance and Palliative Care Australia, *Palliative care in rural and remote areas*, Fact Sheet 34, October 2012, accessed 9 May 2013 from <http://nrha.ruralhealth.org.au/cms/uploads/factsheets/fact-sheet-34-palliative-care-in-rural-and-remote-areas.pdf>

³³⁰ ABS, *Regional population growth, Table 1. Estimated resident population, Remoteness areas, Australia*, available at <http://www.abs.gov.au/ausstats/abs@.nsf/Products/3218.0~2011-12~Main+Features~Main+Features?OpenDocument>

³³¹ White K, Wilkes L, Yates P and Cairns W, *Development of a model for palliative care in rural and remote communities: the ‘pop-up model’*, 2005, p.1, available at <http://www.abc.net.au/rural/events/ruralhealth/2005/papers/popupmodel.pdf>

³³² PCA, Submission no. 69, p.3

³³³ For example, Corina Woodland, Submission no. 6, p.4

³³⁴ St Vincent’s Hospital Brisbane, Submission no. 44, p.5

³³⁵ Kinicare, Submission no. 39, p.5

groups living in remote locations.³³⁶ The committee notes that a palliative care physician has commenced work in Cairns since the submission was written.

Kincare also noted that where specific palliative care services are available they are “often constrained by Local Government or regional funding boundaries.”³³⁷

Primary healthcare providers are pivotal in delivering palliative care in rural and remote areas, and GPs often care for patients throughout the terminal phase of their illness. In some locations local hospitals are able to provide a good standard of care. The committee considers that specialist palliative care consultancy should be readily available to support rural GPs and regional hospitals in this role, and notes that access to GPs who provide after-hours care may be limited. Recommendations about the consultancy-liaison role of specialist palliative care services are made in Chapter 13.

11.3 Travel and accommodation

Some patients from rural and remote areas travel to major centres for treatment, for example, for oncology treatment or dialysis. They may remain in that centre, away from family, during the terminal phase of their illness, contributing to increased costs and isolation.³³⁸ In some rural and remote locations distances and limited transport options mean that commuting for treatment or for family to visit a patient is not realistic. Palliative patients and their families therefore relocate to be near treatment and hospices and palliative care units.³³⁹ One submitter described her personal experience of end-of-life care for both of her parents, which was preceded by their re-location from a rural area to Brisbane to be close to oncology treatment.³⁴⁰

These changes place a considerable burden on patients and their families. “It is costly. They are paying hotel fees to access services that really should be able to be accessed locally.”³⁴¹ Micah Projects informed the committee that people who travel from regional areas to Brisbane for treatment sometimes lose their housing and then live in their car.³⁴²

The committee notes that in January 2013, subsequent to submissions received by the committee, the level of subsidy available under the Patient Travel Subsidy Scheme was increased. The increase in subsidy level does not address all of the travel issues raised by stakeholders, but should address the needs of some patients and families. Other travel and accommodation issues may be avoided by progressive development of the capacity to provide care using a palliative approach in the general health and care workforce, the use of videoconference for specialist advice to health providers, and for remote consultations.

11.4 Improving access and equity

In evidence to the committee the President of Palliative Australia said that “We need to address the need for care in all places of a state as large as Queensland and that will require some very inventive processes.”³⁴³ The committee recognises that it is not possible to have a specialist palliative care service physically accessible to every Queenslanders. It believes, however, that access to specialist advice and expertise for people in rural and remote areas can be expanded by improving planning and the capacity of specialist palliative care services to provide consultation services to GPs and other health care providers. This, combined with work to improve health providers’ knowledge of a

³³⁶ Cairns and Hinterland Hospital and Health Service, Submission no. 37, p.1, citing: Jong, KE, Vale, PJ and Armstrong BK, ‘Rural inequalities in cancer care and outcomes’, *MJA*, January 2005, Vol.182, No.1, pp.13–4

³³⁷ Kincare, Submission no. 39, p.5

³³⁸ Blue Care and UnitingCare Health, Submission no. 24, p.9

³³⁹ Greater Metro South Brisbane Medicare Local Ltd., Submission no. 55, p.5

³⁴⁰ Fiona Darroch-Speedie, Submission no. 40

³⁴¹ Kerri-Anne Dooley, *Public Hearing Transcript*, 22 August 2012, pp.9–10

³⁴² Micah Projects Inc., Submission no. 18, p.5

³⁴³ Dr Scott Blackwell, *Public Hearing Transcript*, 22 August 2012, p.2

palliative approach, effective use of telehealth and videoconferencing and 24-hour clinical advice, could improve access to palliative care in rural and remote areas.

Several witnesses suggested that access to 24-hour telephone support from clinicians would address some challenges for rural and regional access to palliative care.³⁴⁴ For specialist paediatric palliative care advice, the Queensland Clinical Senate suggested development of a 24-hour state-wide phone support service, using a managed network to improve service provision in regional areas.³⁴⁵

In addition there is potential to improve access to services by developing the capacity of regional and remote health service providers to provide care using a palliative approach. Professional development and training opportunities are much harder to access from regional and remote areas. The committee was told by a service provider that arrangements for staff to attend palliative care training in Brisbane were not realised when training was cancelled and that “(i)t is very difficult to get the training out here. They bypass us along the coast.”³⁴⁶ Specialist palliative care services that have the capacity to provide training in a palliative approach should be encouraged to deliver training in ways that are accessible to rural and remote service providers.

The committee’s recommendations about specialist palliative care services, including consultation services and access to 24-hour clinical advice are in Chapter 13. Professional development and capacity building by specialist palliative care services are discussed in Chapter 13 and Chapter 14 and use of telehealth and videoconferencing is discussed in Chapter 15.

Supporting the capacity of carers to provide home care is also critical to enabling people in rural and remote areas to remain at home, if that is their wish. *Part 5* addresses support for carers. Training health care providers with expertise in palliative care or a palliative approach is an important way to improve access to services in rural and remote areas, and is discussed in Chapter 14.

³⁴⁴ For example, Carol Hope, *Public Hearing Transcript*, 24 August 2012, p.16

³⁴⁵ Queensland Clinical Senate, Submission no. 63, p.2

³⁴⁶ Helen Davis, Community Service Manager, Blue Care, *Public Hearing Transcript*, 4 February 2013, p.11

Chapter 12. Palliative care in community settings

*The vast majority of palliative care can and does take place in the community. It takes place effectively, safely and efficiently.*³⁴⁷

12.1 Introduction

Many people can receive adequate palliative care at home from primary health care providers, supported by specialist services as required. This chapter discusses palliative care services in community settings, that is, care provided outside hospital. As well as care in a person's home, community settings include general practice and other primary health care services, hospices, hospice in the home, Hospital in the Home, and residential aged care facilities, including specialist 'in-reach' services. General practitioners, nurse practitioners, nurses, and allied health professionals are important in providing a palliative approach to health care. Patients and families are often supported by staff of non-government organisations, volunteers, and unpaid carers. In residential aged care settings, enrolled nurses, assistants in nursing and personal care workers are also important members of the multi-disciplinary team delivering a palliative approach.

This chapter discusses general practice and home care, palliative care in residential aged care, followed by discussion of issues that are relevant to both home care and RACF care. Specialist palliative care services are discussed, but dealt with in more detail in Chapter 13. The need to develop the workforce capacity required to achieve better access to quality palliative care is central to discussion of palliative care in both community and specialist settings, in this and the next chapter. Chapter 14 focuses on workforce capacity issues, including professional development and training.

12.2 General practice and home care

The committee understands that most people with a terminal condition prefer to receive care at home for as long as possible, and that not everyone needs specialist palliative care services. The importance of providing care in the setting of choice, combined with the high cost of inpatient hospital care, means that it is critical that Queensland increase its capacity to deliver a palliative approach in the community, including residential aged care facilities.

The Royal Australasian College of Physicians (RACP) noted that the primary site of care for many people at the end of life, particularly those with non-malignant conditions, is in the community or in RACFs.³⁴⁸ The committee was told of two Australian studies that indicate that 75 per cent of GPs see palliative care as a central part of their care.³⁴⁹ A 2012 survey by Greater Metro South Brisbane Medicare Local of the 1,033 GPs in its area reports significant interest by GPs in palliative care. Of the 56 respondents, 34 (61 per cent) said they provide palliative care services 'in hours', and 18 said they also offer in-home after hours services.³⁵⁰

Issues affecting GPs' capacity to deliver palliative care for patients at home that were drawn to the committee's attention include:

- the general practice workforce profile
- access to specialist consultation and support for GPs and other primary health care providers to manage complex symptoms

³⁴⁷ Carol Hope, *Public Hearing Transcript*, 24 August 2012, p.14

³⁴⁸ RACP, Submission no. 25, p.4

³⁴⁹ Professors Geoff Mitchell and Xavier Gomez-Batiste, Submission no. 52, pp.1–3, citing: Reymond E, Mitchell G, McGrath B and Welch D, *Research into the educational, training and support needs of general practitioners in palliative care*, Report to the Commonwealth of Australia, 2003, Brisbane, Mt Olivet Health Services; and Rhee J, Zwar N, Vagholkar S, Dennis S, Broadbent AM and Mitchell G, 'Attitudes and barriers to involvement in palliative care by Australian urban general practitioners' *Journal of Palliative Medicine*, 2007, Vol.11, No.7, pp980–5

³⁵⁰ Greater Metro South Brisbane Medicare Local Ltd., Submission no. 55, p.6

- clinical and care records, particularly the absence of a single unified record
- remuneration for GPs
- medication needs for care at home and in residential aged care facilities, and
- knowledge and training in palliative care

Most of those issues were echoed in the Medicare Local survey mentioned above. It reported that factors influencing GPs involvement in palliative care included the time required for palliative care, financial incentives, fragmentation across medical and allied health providers and GP knowledge of palliative care.³⁵¹

12.2.1 General practice workforce

Submissions and witnesses commented on the changing general practice workforce and the declining number of GPs who offer after hours and home visiting services, which are commonly required for palliative care at home. Professor Reymond described the profile of general practice and its effect on palliative care:

*... a GP workforce that is corporatized, part-time and which makes fewer home visits while increasingly using deputising services for after-hours care. GP practice is geared progressively towards providing episodic care in short surgery-based consultations. Such practice is a significant barrier to providing effective palliative care as it is not conducive to the provision of holistic palliative care and impacts many people's preferred option of dying at home.*³⁵²

Professor Mitchell refers to the 'looming problem', that the profile of GPs who are not willing to be involved in palliative care is very close to significant sections of the future GP population; that is, younger GPs, non-Australian trained, employees rather than practice owners, part time and female.³⁵³

The experience of one GP in a practice of 14 doctors reflects this trend; he said that GPs who work part-time "...are very disinterested in palliative care. It does not sit well with their family routines and it is unpredictable".³⁵⁴

A number of submissions highlighted the importance of having enough GPs who are willing, educated and skilled to provide palliative care in the community.³⁵⁵ The Australian Medical Association Queensland (AMAQ) stated that doctors must be educated about palliative care options and the palliative approach to care, so they are well-equipped to offer choice of treatment to their patients. This allows patients to make informed choices for themselves and their families.³⁵⁶ The Royal Australian College of General Practice (RACGP) submitted that GPs are skilled in managing uncertainty and complexity, and, with appropriate support and resourcing, are ideally placed to play a central role in the co-ordination and management of palliative care patients and their families.³⁵⁷ Professor Geoff Mitchell submitted that facilitating GP care of people who are in the final stages of life, "utilizing a palliative approach will facilitate improved care and almost certainly reduce unplanned hospital admissions".³⁵⁸

Professor Mitchell highlighted a mismatch between some GPs perception of palliative care, and the care that they are currently delivering for patients with advanced chronic disease. He suggested that

³⁵¹ Greater Metro South Brisbane Medicare Local Ltd., *ibid.*, p.6

³⁵² Professor Liz Reymond, Submission no. 11, p.10

³⁵³ Professors Geoff Mitchell and Xavier Gomez-Batiste, , Submission no. 52, p.4, citing: Mitchell GK, Johnson CE, Thomas K, Murray SA 'Palliative care beyond that for cancer in Australia', *MJA*, July 2010, Vol.193, No.2, pp.124–6

³⁵⁴ Dr Martin McGahan, *Public Hearing Transcript*, 5 February 2013, p.3

³⁵⁵ St Vincent's Hospital Brisbane, Submission no. 44, p.10, Professor Liz Reymond, Submission no. 11, p.10

³⁵⁶ Australian Medical Association Queensland (AMAQ), Submission no. 67, p.2

³⁵⁷ RACGP, Submission no. 58, pp.1–2

³⁵⁸ Professors Geoff Mitchell and Xavier Gomez-Batiste, *ibid.* p.1

some GPs are caring for palliative patients, but may not recognise this.³⁵⁹ If unrecognised, it is possible that the patients may not receive the benefits of a palliative approach.

The committee considers that there is value in encouraging more GPs to provide palliative care, but recognises that not all GPs will be interested, and not all are able to provide the after-hours care which is often required. There is however potential to encourage and support GPs to be involved in palliative care by improving GPs knowledge of palliative care (see Chapter 14 *Workforce capacity*), and improving their access to consultation services and after hours care provided by specialist palliative care services.

12.2.2 Access to specialist consultation services and shared care arrangements

Specialist palliative care services have an important role in supporting general practitioners and other primary health care providers. That support is not consistently available to GPs. Some, but not all of Queensland's public sector specialist palliative care services provide consultation and liaison support to GPs. Some services also have shared care arrangements where a GP provides most of the medical support for a palliative patient, supported by the specialist palliative care service when needed. Specialist palliative care services that provide a 24-hour on-call service are well placed to work with GPs in shared care arrangements, if they have adequate resources to do so. On call community care services may be staffed by a nurse practitioner or specialist palliative care nurse, backed up by access to a palliative care physician if required.

There is emerging evidence that early identification of patients who may benefit from palliative care leads to better co-ordination of care. Similarly, early referral to specialist palliative care when patients' life expectancy is six to 12 months can lead to more appropriate care in the place of the patient's choice, higher satisfaction with care, and more efficient care.³⁶⁰

Professor David Currow noted that many general practitioners provide unparalleled care for people with terminal conditions. "The interface with primary care is crucial for good palliative care to be delivered across the nation. Some services have systematically disenfranchised primary care, and this will come at a cost to patients (in terms of continuity) and sustainability of services..."³⁶¹ The RACGP supported resourcing specialist palliative care services to provide ongoing education and support, and to provide consultation and shared care with GPs, particularly those working in rural and remote communities.³⁶²

Professor Mitchell suggested that encouraging GPs to participate in palliative care may involve broadening their perspective about patients who are already recognised as seriously ill, frail or both, but may not be recognised as palliative. This requires first the recognition that patients may die and therefore need a broader palliative focus. It also requires that GPs have knowledge of what to do to prevent symptoms emerging and how to prepare for symptom care when an expected crisis arises. In addition, there is a need to develop care plans that consider non-medical issues.³⁶³

In Ipswich, a model of facilitating and supporting GPs' provision of palliative care is being trialled. The project, run by the Centre for Research Excellence at the University of Queensland, aims to improve palliative care and is expected to reduce unplanned hospital admissions.³⁶⁴ Professor Mitchell advised that the BASIC-PC (Better Assessment, Support and Interdisciplinary Collaboration – Palliative Care) project is based on early identification of people who may benefit from palliative

³⁵⁹ Professors Geoff Mitchell and Xavier Gomez-Batiste, *ibid.*, p.4

³⁶⁰ Professor Rohan Vora, Submission no. 73, p.6, cites PCA Submission to Senate Committee inquiry, *Palliative care in Australia*, pp.132–4

³⁶¹ Professor David C. Currow, Submission no. 62, pp.8–9

³⁶² RACGP, Submission no. 58, p.3

³⁶³ Professors Geoff Mitchell and Xavier Gomez-Batiste, *ibid.*, p.4

³⁶⁴ Professors Geoff Mitchell and Xavier Gomez-Batiste, *ibid.*, p.1

care, and planning care jointly between the public health system, community based care and the patient's GP.

Patients who are within months of the end of life are identified by Queensland Health heart failure and lung health services. A case conference is held at the GP's surgery between the GP, a palliative care specialist and a nurse case manager. A palliative care plan is developed the nurse and/or GP discuss with the patient what changes could be implemented. The cost of the case conference for the GP and the palliative care specialist is met by Medicare, and community health contributes the cost of the nurse's participation in a case conference.³⁶⁵

Professor Mitchell argues that the case management approach being trialled in Ipswich should be adapted to the broader range of patients in the public hospital system and piloted, including developing and implementing a plan that specifies the roles for hospital-based services, GPs and other community services, and communication between them.³⁶⁶

Committee comment – Specialist palliative care services – consultation and shared care

The committee considers that the provision of consultation and shared care services by specialist palliative care services is essential to facilitating quality palliative care in the community, in line with most people's preferences. It is expected that additional resources will be required to ensure that specialist palliative care services can provide the required level of consultancy and shared care to support accessible palliative care for all Queenslanders.

The committee believes that improved planning and implementation of formalised and systematic arrangements for specialist consultation and liaison services, and increased use of telehealth consultations can improve access to specialist palliative care consultancy and advice to GPs and other health providers.

Specialist palliative care services should have the capacity to provide consultation by telephone and videoconference with smaller palliative care services, other hospitals, general practitioners and residential aged care facilities. The committee believes that an investment in specialist palliative care services to provide consultation services and support home-based care could be offset by a reduction in acute hospital costs from unnecessary and unwanted hospital admissions. The committee's recommendations about specialist palliative care services are in Chapter 13.

12.2.3 Doctor's remuneration for palliative care

Stakeholders raised concerns about the remuneration that is available for palliative care under the Medicare Benefits Schedule. The AMAQ and the RACGP both argued that the level of remuneration that is available for long palliative care consultations, home visits and RACF visits a barrier to GP involvement in palliative care.³⁶⁷ The RACGP noted that there has been some effort at addressing this through the introduction of additional Medicare item numbers; however they assert that the fee for service system does not adequately remunerate the cost of this work.³⁶⁸

Dr Martin McGahan, a GP who cares for palliative patients, including after-hours, acknowledged that funding of private practitioners is an Australian Government issue and commented that "palliative

³⁶⁵ Professors Geoff Mitchell and Xavier Gomez-Batiste, *ibid.*, p.8

³⁶⁶ Professors Geoff Mitchell and Xavier Gomez-Batiste, *ibid.*, pp.8–9

³⁶⁷ AMAQ, Submission no. 67, p.2, RACGP, Submission no. 58, p.1

³⁶⁸ RACGP, Submission no. 58, p.2

care is not particularly well reimbursed". He also noted that travel is sometimes an issue, for example, for home visits to a dying patient who lives out of town.³⁶⁹

Dr Mark Deuble reminded the committee of the importance of high quality palliative care for residents of aged care facilities and said that it is becoming tougher for busy GPs to spend large amounts of their working week in those facilities. He said that "...because of Medicare issues and rebates associated with Medicare, many GPs are forgoing that".³⁷⁰

The committee recognises that remuneration for private medical practitioners is an Australian Government responsibility. In light of the importance of encouraging GPs to provide palliative care, the committee recommends that the Minister for Health raise with the Commonwealth Minister for Health, the issue of the adequacy of remuneration for medical practitioners providing palliative care in the home and in RACFs.

Recommendation 10 – Medicare benefits for GP palliative care

The committee recommends that the Minister for Health ask the Commonwealth Minister for Health to consider whether changes to the Medicare Benefits Schedule should be made for general practitioner consultations, home visits and residential aged care visits and associated travel costs for palliative care to support care in the home.

12.3 Residential aged care facilities – challenges to high quality palliative care

The delivery of palliative care in residential aged care facilities (RACF) is an essential element of ensuring that older people who need palliative care can remain where they live at the end of life, rather than face the disruption of admission to an acute hospital through accident and emergency. The experience of the Council on the Ageing is that "in a lot of cases ... the facility is not equipped to (provide the services) so the person ends up dying in hospital. That is not necessarily the best location for that to happen and obviously puts a strain on hospital services".³⁷¹

The committee was told that "RACFs are the hospices of today and likely to remain so in the future. Nonetheless there is professional consensus that people in RACFs frequently receive less than quality palliative care".³⁷²

As noted in 12.2.1 above, the number of GPs willing to care for residents in RACFs is falling, while they continue to be significant providers of the medical care in those settings. "General practitioners report that they find it difficult to treat their patients in RACFs due to limited organisational support at some RACFs ...".³⁷³ Dr Deuble told the committee that:

... [at] a practical level it means that patients who should be cared for in their home, which is their nursing facility and where their families wish them to be cared for, are commonly transferred to acute facilities such as the hospital I work in and then the outcomes are not what families want".³⁷⁴

The Royal Australasian College of Physicians (RACP) told the committee that it "... is well-recognised that acute, public hospitals are often poor care locations for frail, older people, and particularly for

³⁶⁹ Dr Martin McGahan, *Public Hearing Transcript*, 5 February 2013, p.3

³⁷⁰ Dr Mark Deuble, *Public Hearing Transcript*, 24 August 2012, p.28

³⁷¹ Mark Tucker-Evans, Chief Executive Officer, Council on the Ageing – Queensland (COTA), *Public Hearing Transcript*, 24 August 2012, p.2

³⁷² Professor Liz Reymond, Submission no. 11, p.4

³⁷³ AMAQ, Submission no. 67, p.2

³⁷⁴ Dr Mark Deuble, *ibid.*, p.29

those with dementia".³⁷⁵ The RACP reported that over 50 per cent of residents of RACFs have dementia.³⁷⁶ Professor Rudden reminded the committee that residents who

*... have dementia and cognitive impairment cannot complain to you. They are voiceless and they do not give you any feedback, but they should be able to receive high quality care in the facility without needing to be admitted to hospital.*³⁷⁷

The capacity to provide quality palliative care in RACFs is sometimes complicated by a low staff to resident ratio. There may be only one registered nurse responsible for many residents. Most RACF care staff are not trained to make clinical assessments that might assist in identifying a palliative resident's needs.³⁷⁸

12.4 Achieving high quality palliative care in residential aged care facilities

Good quality care at the end of life can be provided in a RACF if staff and GPs are adequately supported and trained. Specialist palliative care services have an important role in supporting and building capacity to provide quality palliative care in RACFs. The importance of treating residents of aged care facilities 'in place' was acknowledged by the Minister for Health:

*..... We are trying a whole range of innovative models to get people who are aged-care patients in the latter stage of their life to be treated more appropriately in their environment in their nursing home or their home now. ... Working with GPs to treat people in that environment is very important so, yes, there is a range of strategies that we are currently looking at.*³⁷⁹

The committee was informed of a number of models of care for RACF residents, some of which are described below.

12.4.1 National palliative approach toolkit

The national roll-out of a Palliative Approach Toolkit in RACFs is underway during 2012–15, funded by the Australian Government. This work was initiated by the Brisbane South Palliative Care Collaborative (Brisbane South Metro Palliative Care Service, Metro South Hospital and Health Service, and Griffith University) which aims to promote best practice community palliative care through quality improvement projects, education, training and research. The rollout will develop clinical, educational and management resources to support use of existing materials in the Palliative Approach Toolkit, and deliver workshops for RACF managers, clinical leaders and staff trainers on how the Toolkit resources can be used to implement a sustainable approach to palliative care in RACFs.³⁸⁰

12.4.2 End-of-life pathway for residential aged care

A Brisbane study developed, implemented and evaluated an end-of-life care pathway (RAC EoL),³⁸¹ and associated infrastructure for Australian residential aged care facilities. The care pathway was developed to provide a user-friendly final document which "needed to provide a comprehensive template of care that could empower generalist workers to deliver consistent and appropriate

³⁷⁵ RACP, Submission no. 25, p.5

³⁷⁶ RACP, *ibid.*, pp.5–6

³⁷⁷ Professor Ann Rudden, *Public Hearing Transcript*, 22 August 2012, p.12

³⁷⁸ Professors Geoff Mitchell and Xavier Gomez-Batiste, Submission no. 52, p.9

³⁷⁹ Hon. Lawrence Springborg MP, Minister for Health, *Public Hearing Transcript*, 22 August 2012, p.27

³⁸⁰ Professor Liz Reymond, Submission 11, p.4; and Reymond E, 'National implementation of the Palliative Approach Toolkit for residential aged care facilities', *ANZSPM Newsletter*, March 2013, Vol.25, No.1

³⁸¹ The care pathway is a document intended to prompt assessment, management and documentation of a resident's needs and care requirements.

palliative care and which complied with jurisdictional and workplace constraints”.³⁸² In addition to the RAC EoLCP, the study implemented education and training for RACFs, communication strategies to ensure buy-in from RACFs, GPs and specialist palliative care services, a medication imprest system in participating RACFs, and telephone support for GPs from a palliative care specialist and for RACF staff from a nurse practitioner. The primary outcome measure of the study was transfers from the RACF to hospital.

During the implementation period, the proportion of RACF residents transferred to hospital at end-of-life was significantly less for those on the RAC EoLCP (1.7 per cent) than for residents not commenced on the RAC EoLCP (21.5 per cent). Staff at participating RACFs saw an improvement in the quality of the palliative care provided, and were more satisfied with the care. Implementation of the RAC EoLCP was found to guide the delivery of high quality palliative care and to act as an educational tool to develop the capacity of generalist staff. It enabled more residents of RACFs to die ‘in place’ rather than in hospital, which has “positive economic implications for the Australian health system”.³⁸³

After one of the RACFs operated by Wesley Mission Brisbane participated in the RAC EoLCP study, it conducted a project to translate that research evidence into practice in all of its RACFs. During the course of the project over 1,000 Wesley Mission Brisbane staff attended education and received workplace mentoring and support.

*A major component of the project was to up skill senior clinicians to be the experts in a palliative approach to care. [Wesley Mission Brisbane] now has specialised Clinical Nurse Consultants and Palliation Advisors to continue to implement and support the use of the EoLCP and ensure the best possible end-of-life care in all our aged care services. As a result of this project the number of transfers of residents at end-of-life rapidly decreased and this transfer rate remained low throughout the project and continues to minimal today.*³⁸⁴

12.4.3 Specialist visiting services and ‘in-reach’ services

St Vincent’s Hospital Brisbane and Caritas Care, which operates seven RACFs, have introduced a successful visiting specialist geriatrician service. A geriatrician visits each RACF to consult with patients, provide advice, support and education to staff and visiting GPs. The service aims include improving residents’ access to specialist care, preventing the need for unnecessary hospital admission or crisis management, providing guidance for GPs and staff and referring residents to other specialist medical services as appropriate.³⁸⁵ St Vincent’s is now planning to introduce a ‘hospital in the nursing home’ model of care.

The Metro South Hospital and Health Service has established a RACF palliative care service that in-reaches to 76 facilities, or 98 per cent, of the RACFs in the HHS area. The service is led by a nurse practitioner. The service has significantly reduced the number of inappropriate referrals and admissions of palliative RACF patients to emergency departments.³⁸⁶

12.4.4 Age appropriate care

Youngcare drew the committee’s attention to the estimated 7,500 Australians under 65 with high care needs who, in the absence of age-appropriate alternatives, live in residential aged care facilities. In addition to advocating for age appropriate accommodation and care for younger adults,

³⁸² Reymond L, Israel F and Charles M, ‘A residential aged care end-of-life care pathway (RAC EoLCP) for Australian aged care facilities’, *Australian Health Review*, August 2011, Vol.35, No.3, p.350–356, p.351

³⁸³ Reymond, Israel and Charles, *ibid.*, p.355

³⁸⁴ Wesley Mission Brisbane, Submission no. 26, p.2

³⁸⁵ St Vincent’s Hospital Brisbane, Submission no. 44, p.8

³⁸⁶ Professor Liz Reymond, Submission no. 11, p.4

Youngcare argued that a young person's end of life care needs will not be met in a residential aged care facility, as their needs differ from those of an older person.³⁸⁷ Youngcare said that:

*As in life, Australians should expect to have self-determination and control of their environment and condition management at their end of life; to be an active participant over when, where, how and with whom. The person, loved ones and carers are supported before, during and after. It is evident that you don't need to be old to need palliative care.*³⁸⁸

The committee considers that efforts by specialist palliative care services to support high quality palliative care in residential aged care facilities should include advice and support for staff to provide age appropriate palliative care for younger adults as well as the aged.

12.5 Medication – access at home and in residential aged care

The committee heard that timely access to appropriate medications can be problematic for palliative patients who are cared for at home or in a RACF, particularly because a patient's symptoms may change quickly. If a patient's medical care is provided by a GP or a specialist palliative care service that does not provide after-hours care or home visits, or if plans have not been made to deal with changing needs, the result may be an avoidable hospital admission.

A private hospital specialist palliative care service summarised the issue:

*... patients' conditions change rapidly, and they often require changes to their medications. There is some reluctance for some GPs to provide scripts for patients without reviewing them, so it can mean that patients run out of medications and their symptoms become unable to be managed and they re-present at hospital.*³⁸⁹

Another specialist palliative care service, which has an after-hours on-call service, described the problem and the solution for patients registered with the specialist service and cared for at home:

*Palliative care patients are inherently unstable and symptoms can emerge at any time and need to be treated, often pharmacologically. Community pharmacies do not always stock medications prescribed by specialist palliative care doctors. To facilitate patients remaining at home for as long as possible the MSPCS has a small stock of palliative care drugs that can be immediately provided to patients as required and that can tide them over whilst awaiting delivery of medications from their local pharmacist.*³⁹⁰

The Metro South Palliative Care Service has worked (MSPCS) with RACFs to develop palliative care medication imprest systems, and standing orders to support symptom control in palliative residents. This system allows for immediate symptom control for residents, until GPs can provide prescriptions, and decreases transfers to acute hospitals, as well as improving the quality of life and death for RACF residents. Professor Liz Reymond recommended that Level 6 specialist palliative care Medicare Locals work in partnership to establish palliative care medication imprest systems for RACFs and standing orders.³⁹¹

The AMAQ suggested that a solution in RACFs that would streamline prescribing would be to amend legislation to allow chart-based prescribing in RACFs. Their submission stated that "Commonwealth legislation has been passed to support Pharmaceutical Benefits Scheme subsidies for prescriptions made in this way and trials are currently underway in NSW".³⁹² The AMAQ reinforced this at a public hearing, stating that "(a)nything, such as things to make medication writing easier for GPs, allowing

³⁸⁷ Youngcare, Submission no. 10, p.1

³⁸⁸ Youngcare, *ibid.*, p.2

³⁸⁹ Professor Janet Hardy and Decima Jones, Submission no. 16, p.5

³⁹⁰ Professor Liz Reymond, *ibid.*, p.15

³⁹¹ Professor Liz Reymond, *ibid.*, p.18

³⁹² AMAQ, Submission no. 67, p.3

them to give medications over the phone and faxing medication lists, would make their job much easier.³⁹³

In its submission Palliative Care Nurses Australia recommended that current restrictions on prescribing by nurse practitioners should be removed so that they can practise according to their scope of practice.³⁹⁴ The committee notes that under the *Health (Drugs and Poisons) Regulation 1996* endorsed nurse practitioners can prescribe, give a written or oral instruction, supply, and administer the controlled and restricted drugs or poisons that are necessary to practise nursing within the approved practice scope of the position in which the nurse practitioner is engaged.³⁹⁵

The committee considers that expanding the number of nurse practitioners is a key part of ensuring that Queensland's palliative care workforce can meet needs (see discussion in Chapter 14 *Workforce capacity*). In that context, the committee believes that any barriers to nurse practitioners prescribing or supplying palliative care medications should be examined. While some medication needs can be addressed by good planning, the inherently unstable symptoms of people nearing the end of life means that flexibility is required to meet people's need to approach death without unnecessary pain or distressing symptoms.

The committee notes that it is not clear whether legislative amendments are required, or whether there may be a need to provide information to raise awareness of what nurse practitioners in palliative care are able to prescribe and supply.

The committee therefore recommends that the Minister ask Queensland Health to consult with nurse practitioner and other stakeholders about any concerns about medication in palliative care, and consider any needed amendments to legislation. The committee also recommends that the Minister promote the implementation of medication imprest systems in RACFs with the support of public sector specialist palliative care services in partnership with general practice stakeholders including Medicare Locals.

Recommendation 11 – Medication in community settings

The committee recommends that the Minister for Health consult with medical, nurse practitioner, RACF and pharmacy stakeholders and consider whether amendments to legislation are needed to facilitate more streamlined prescribing for patients in residential aged care facilities, and for palliative patients who receive care at home, including:

- 'chart-based prescribing' by medical practitioners
- any restrictions on nurse practitioners prescribing and supply of medications commonly used for pain management in palliative care, or supply of medications by nurses.

³⁹³ Dr Mark Deuble, *Public Hearing Transcript*, 24 August 2012, p.29

³⁹⁴ Palliative Care Nurses Australia Inc., Submission no. 46, p.4

³⁹⁵ Queensland Health, *Drug Therapy Protocol for Nurse Practitioners*, July 2010, effective January 2011, accessed 12 April 2013 from <http://www.health.qld.gov.au/ph/documents/ehu/30472.pdf>

Recommendation 12 – Medication in residential aged care systems

The committee recommends that the Minister for Health work to ensure that public sector specialist palliative care services collaborate with residential aged care facilities (RACF) and general practitioners and Medicare Locals, to develop RACF medication systems that facilitate prompt access to needed medications for palliative patients, while ensuring the safety and security of medications and residents. This should include consideration of:

- Queensland Health as system manager including in service agreements or other instruments a requirement that Level 6 specialist palliative care services initiate action to implement suitable medication systems in collaboration with RACFs and organisations that represent general practitioners
- providing resources for palliative care services to develop suitable medication systems in collaboration with RACFs and general practitioners
- flexible medication models that are suitable for each location and consistent with legal requirements.

12.6 Single electronic patient clinical record

Several witnesses mentioned the benefits for patient care and co-ordination that would result from use of a single electronic patient clinical record. The Royal Australian College of General Practitioners argued that a single medical record, used by all care providers, is needed to ensure safe, comprehensive, coordinated whole of patient care.³⁹⁶

As quality palliative care requires a multi-disciplinary approach, an electronic record that can be accessed by health providers and organisations providing home care would be ideal. Karuna Hospice, which provides in-home hospice care, argued that an electronic health record is pivotal to providing multi-disciplinary 24-hour care. An electronic record is particularly relevant where a patient has complex needs, and a range of health providers may be involved in care. A single electronic record could also be a tool for multidisciplinary collaboration.³⁹⁷

The Brisbane Metro South Palliative Care Service has responded to the need for all clinicians involved in providing palliative care to access an up to date patient record by developing a web-based record. The record can be accessed by all of the palliative care service staff, whether the patient is in hospital, seen as an outpatient, or visited at home.³⁹⁸

Electronic health records and telehealth applications are discussed further in Chapter 15.

Committee comment – Electronic health records

The potential benefits of a system of electronic health records accessible to all clinicians and carers and with appropriate security and privacy safeguards have been much discussed in recent years. The committee considers that further development of a national system of electronic health records is critically important. The committee encourages the Minister to support further development of electronic health records that can be used across public and private health and care services to improve co-ordination of health care, including palliative care.

³⁹⁶ RACGP, Submission no. 58, p.1

³⁹⁷ Catherine Mickel, *Public Roundtable Discussion Transcript*, 14 November 2012, pp.4 & 16

³⁹⁸ Professor Liz Reymond, Submission no. 11, p.5

12.7 Carers' needs

12.7.1 Respite care

A significant factor in whether patients with a terminal illness are able to remain at home is the capacity of unpaid carers, usually family and friends, to provide the level of direct care that the person needs. Home care is usually challenging, even for those who are highly motivated and have sufficient time to devote to care. A hospice described the carer requirements for palliative care and death at home as: an able-bodied responsible carer; assistant carer/s who live in or near the home; personal and financial circumstances that allow time for full-time caring; and excellent communication between the patient and carers.³⁹⁹ The demands of caring for a person with a terminal illness are considerable, and respite care is a critical factor in supporting carers so that they can continue in that role. Respite care and other support for carers are discussed in Chapter 22.

12.7.2 Support and training about palliative care

The committee heard from both service providers and carers about the importance of carers receiving information, support and training about aspects of dying and care, including use of specialised equipment, medication, expected symptoms and issues such as safe lifting. The committee makes recommendations about general support for carers in Chapter 22 of this report.

It is important that palliative care providers ensure that carers are provided with sufficient support and information to manage home care. UnitingCare noted that carers may need to attend to equipment and administer medication, including through syringe drivers.⁴⁰⁰ The Centre for Palliative Care and Research Education has developed a self-directed learning package for health professionals includes information on educating carers on syringe driver operation to ensure effective administration of medication if the healthcare provider is not immediately available.⁴⁰¹

Professor Reymond told the committee that the likelihood of patients symptoms remaining well managed at home often depends on family members to administer subcutaneous medications. Carers have reported that their ability to provide injections adds value to patient care; nonetheless many report the need for education and resources to assist them in this quasi-professional role. A package of resources has been developed to educate and support carers to draw up, store and administer subcutaneous injections, monitor injection sites, manage a medication administration record suitable for easy assessment by health providers, and to show the uses of common medications used in palliative care. This resource package has been rolled out to all community palliative care services in Victoria.⁴⁰²

The arrangements required after death can also be a source of stress for carers and families. The cost of a funeral and how it will be covered can be a particular concern. Assistance in arranging funerals may be provided as a part of the holistic care offered by palliative care workers.⁴⁰³ The committee also notes that the Department of Justice and Attorney-General, through the Office of State Coroner or a local Magistrates Court Registry, will organise burial or cremation (although not a funeral service) where the person's assets cannot cover those costs.

The committee believes that the information and training needs of individual carers will vary considerably, and encourages health providers in palliative care to ensure that tailored information and training is offered to carers to support them in their role.

³⁹⁹ Ipswich Hospice Care Inc., Submission no. 59, pp.16–7

⁴⁰⁰ Blue Care and UnitingCare Health, Submission no. 24, p.9

⁴⁰¹ Queensland Health, *Syringe Driver Management in Palliative Care* available at http://www.health.qld.gov.au/cpcrc/pdf/cpcrc_sd_gdlnr.pdf

⁴⁰² Professor Liz Reymond, Submission no. 11, p.16

⁴⁰³ Mary Cotterell, *Public Hearing Transcript*, 4 February 2013, p.12

Recommendation 13 – Greater awareness of burial assistance

The committee recommends that the Minister for Health ensure that all Hospital and Health Services with a palliative care service provide information on the burials assistance provided by the Department of Justice and Attorney-General to patients and carers when needed.

12.8 Equipment for home care

Timely access to affordable specialist equipment is often required for home care of a person with a terminal condition. A number of submissions described difficulties carers faced in obtaining the specialised equipment needed to care a person at home. The equipment needs of clients of Queensland Community Care Services, who commonly need equipment for longer periods, are discussed in Chapter 20.

Palliative patients often need to access equipment quickly and may only require it for relatively short periods of time. Occupational Therapy Australia suggested there should be an equipment pool, which can be accessed quickly and efficiently, and ensures that urgent requests for equipment are met.⁴⁰⁴

Blue Care and UnitingCare Health described difficulties with accessing specialised, palliative care equipment. Items are often in limited supply, difficult to get hold of at short notice, expensive to hire and purchase, particularly when they are generally required for only a short period of time. Storage may also be an issue with larger items such as beds. All of these factors are exacerbated in rural and remote areas, where there are fewer services and distances are greater.⁴⁰⁵

12.8.1 Equipment loan services

Some public sector palliative care services provide an equipment loan service. For example, Metro South Palliative Care Services (MSPCS), in the Brisbane Metro South Hospital and Health Service, has established an affordable equipment loan system for palliative patients. Commonly used palliative care equipment, such as hospital beds, has been purchased by the palliative care service and is stored, maintained, delivered and set up in clients' homes by a contracted provider. The provider also dismantles, collects and cleans the equipment once it is no longer required by the client.⁴⁰⁶ Financial pressures on clients are eased as "expensive items are funded directly by MSPCS, while smaller items are funded partially by the patient/family".⁴⁰⁷

Cairns and Hinterland Hospital and Health Service (CHHHS) also have a palliative care equipment pool for clients and stated this is a "key aspect in ensuring smooth transition to community for palliation". The CHHHS submission suggests that lack of equipment results in longer stays in acute hospital beds.⁴⁰⁸

Silver Chain, a non-government provider of home palliative care support in Western Australia, South Australia and Queensland, ensures the provision of equipment 7 days a week.⁴⁰⁹

The committee notes that the Queensland Clinical Services Capability Framework for Public and Licensed Private Health facilities (described in Chapter 4), requires Level 1 to Level 6 palliative care services to "have access to equipment hire services".⁴¹⁰ The committee considers that every Hospital and Health Service which has a palliative care service should operate an accessible equipment loan

⁴⁰⁴ Occupational Therapy Australia, Submission no. 47

⁴⁰⁵ Blue Care and UnitingCare Health, *ibid.*, p.9

⁴⁰⁶ Professor Liz Reymond, *ibid.*, p.4

⁴⁰⁷ Professor Liz Reymond, *ibid.*, p.14

⁴⁰⁸ Cairns and Hinterland Hospital and Health Service, Submission no. 37, p.2

⁴⁰⁹ Silver Chain, Submission no. 31, p.6

⁴¹⁰ Queensland Health, *Clinical Services Capability Framework for Public and Licensed Private Health Facilities, v3.1*, Section 24 Palliative Care Services, p.4

service or contract a provider to operate a service on its behalf, or alternatively make clear arrangements with another HHS for the timely loan of palliative care equipment to patients who are cared for at home.

Recommendation 14 – Equipment loan services

The committee recommends that the Minister for Health ensure that all Hospital and Health Services with a palliative care service operate, directly or through another provider, an accessible equipment loan service for home care to provide timely loan of palliative care equipment to patients who are cared for at home.

12.9 Hospital in the home and hospital in the nursing home

Hospital in the home (HITH) provides acute or subacute treatment in a patient’s residence for a condition that would normally require admission to hospital. A recent meta-analysis of HITH studies noted that the literature is confusing because the term HITH is used variably; some studies do not describe services as HITH, and others described as HITH but do not involve substitution of care at home for in-hospital care.⁴¹¹

The studies analysed dealt with a range of diagnoses and circumstances. Caplan et al found that that overall the cost of HITH was 73.5% of the average cost for the control groups who received in-hospital care.⁴¹² The reduction in cost may have been an underestimate, as costings during trials are usually during introduction of a new model of care, when efficiency is reduced.⁴¹³ Carer satisfaction was assessed in eight studies and was higher in HITH for six, the same in one study, and higher in the control group in one other. Eight of 11 studies showed lower carer burden in HITH.⁴¹⁴

Deloitte Access Economics prepared an economic analysis of HITH for the Hospital in the Home Society of Australasia in 2011, using cost data for a number of diagnostic groups (not including palliative care). They found the costs per hospital separation were less than for in-hospital care, and ranged from 72 per cent of hospital costs for treatment of cellulitis to 96 per cent for respiratory infection.⁴¹⁵ The weighted average cost of HITH was 78 per cent of the cost of hospital care, that is, the cost of HITH was 22 per cent less than hospital care.⁴¹⁶

The Queensland Nurses Union and Palliative Care Nurses Australia both point to “Hospital in the Nursing Home” program run by Royal Brisbane and Women’s Hospital as a program that has reduced inappropriate admissions to acute hospital care.⁴¹⁷

The Minister told that committee that there “is a range of ideas now coming forward in terms of a hospital in a nursing home so we can continue to provide services in that environment where people are often far more comfortable than being brought into an emergency department ...”⁴¹⁸

⁴¹¹ Caplan G, Sulalman N, Mangin D, Aimonino Ricauda N, Wilson A, Barclay L, ‘A meta-analysis of “hospital in the home”’ *MJA*, 5 November 2012, Vol.197, No.9, pp.512–9

⁴¹² Caplan *et al.*, *ibid.*, p.515

⁴¹³ Caplan *et al.*, *ibid.*, p.512

⁴¹⁴ Caplan *et al.*, *ibid.*, p.515

⁴¹⁵ Deloitte Access Economics, *Economic Analysis of Hospital in the Home (HITH)*, Hospital in the Home Society of Australasia, 2011

⁴¹⁶ Deloitte Access Economics, *ibid.*, p.40

⁴¹⁷ Palliative Care Nurses Australia Inc., Submission no. 46, p.6

⁴¹⁸ Hon. Lawrence Springborg MP, *Public Hearing Transcript*, 22 August 2012, p.27

Queensland Health, as system manager, has set a target of 1.5 per cent of all inpatient admissions (which could include some palliative care admissions) to be managed as HITH. Service agreements state:

A target of 1.5% of all inpatient admissions to be managed within Hospital in the Home (HITH) has been set. Admissions to be converted from inpatient to HITH have been funded at 63% (based on nationwide review of HITH costs) of the inpatient tariff. This model assumes substitution of acute care. As part of this change, 63% funding will also be provided for noncomplex cellulitis which was the subject of the 2011–2012 purchasing initiative.

Committee comment – Encourage Hospital in the Home

The committee considers that Hospital in the Home (HITH) initiatives have the potential to deliver high levels of patient and carer satisfaction, provided adequate support exists for carers. Queensland Health should encourage use of palliative care Hospital in the Home as a substitute for acute inpatient care. The committee notes that the economic analysis of HITH does not appear to have compared costs for palliative care.

12.10 Death at home

Successful home care for people with a terminal illness means that death will occur in place, in the person’s home or RACF. Palliative Care Queensland raised issues for health providers, palliative care patients and carers in the community, about the roles of the Queensland Ambulance Service (QAS), Queensland Police Service (QPS) and the funeral industry when an expected death occurs at home.⁴¹⁹

12.10.1 Certification of cause of death

Requirements for certification

In Queensland a cause of death certificate must be completed by a doctor who is “able to form an opinion as to the probable cause of death” within two working days of death. A doctor may be able to appropriately form an opinion about the cause of death by, for example, speaking to a doctor who attended the person when they were alive. Examples in the *Births, Deaths and Marriages Registration Act 2003* make clear that the certifying doctor need not have treated the person.⁴²⁰ If a cause of death certificate is not likely to be issued promptly, a life extinct form can be completed by a medical practitioner, a registered nurse, a paramedic and, in the case of an ‘obvious’⁴²¹ death, a police officer. The person completing the life extinct form must be able to state the name of the doctor who will issue the death certificate;⁴²² otherwise it becomes a ‘reportable death’ under the *Coroners Act 2003*.

After a death at home

Palliative Care Queensland told the committee that “stressed family members call the ambulance service or police service when someone dies, rather than the palliative care service”. Often a death is

⁴¹⁹ PCQ, Submission no. 74, p.51

⁴²⁰ *Births Deaths and Marriages Registration Act 2003*, section 30, available at <http://www.legislation.qld.gov.au/LEGISLTN/CURRENT/B/BirthsDMA03.pdf>

⁴²¹ ‘Obvious’ deaths are those where the state of the body is clearly incompatible with life, e.g. severe incineration, decapitation. Queensland Government, *Life Extinct Form*, accessed 26 April 2013 from <http://www.brisbanesouth.com.au/content/Document/Resources/Aged%20Care/Templates/Life%20Extinct%20Form.pdf>, p.2

⁴²² Queensland Government, *ibid.*, p.1

after hours when “there can be significant difficulty locating a clinician to sign a life extinct form”.⁴²³ If a doctor is not available to visit after hours to issue a death certificate or life extinct form “the police are usually called and an expected death can become a coroner’s case. This is particularly distressing for families.”⁴²⁴

Calling the ambulance or police affects the treatment of a person who is expected to die and has chosen to remain at home and how the home is treated.⁴²⁵ Attempts may be made to resuscitate a person whose death was expected, and the person’s home may become a crime scene. The Queensland Police Service, if there is no “clear information and documentation” about the expected death of a palliative patient, deals with a person’s home as crime scene.⁴²⁶ Most funeral directors insist on a completed life extinct form before removing a body from home, although PCQ advised that there is no formal requirement for a life extinct form.⁴²⁷

Ambulance guidelines

The QAS clinical practice guideline on recognition of life extinct states that police are “to be notified of all deaths” and also notes that the QPS is to be “provided with information that will assist the police to determine if the death is a reportable death as defined in the *Coroners Act 2003 (Qld)*”.⁴²⁸ The guideline gives an example of a death that is clearly not reportable:

*An example of a death that is clearly not reportable is one that is an expected outcome of a diagnosed condition, and the patient’s medical practitioner has indicated that he or she will issue a death certificate.*⁴²⁹

The example implies that only the person’s treating doctor can issue the death certificate, which differs from the examples in the *Births, Deaths and Marriages Registration Act 2003*.

The committee noted that documentation given to the carers of palliative patients in Western Australia explains when, and if, to call an ambulance and what to expect as death approaches. It reminds carers to call a palliative care or community care service before calling an emergency service. The guide encourages carers to have a plan of what to do when death occurs and advises that it is not necessary to call the police or ambulance.⁴³⁰

12.10.2 Expected death – recognition of advance planning documents

Concerns were raised about attempts to resuscitate a patient whose death was expected and the recognition of end-of-life planning documents by ambulance officers. The committee recognises the ethical and legal complexity of some situations discussed. Advance care planning and Advance Health Directives are discussed in Chapter 17.

In Queensland Health facilities an Acute Resuscitation Plan (ARP) for an adult at risk of an acute deterioration may document decisions about future acute treatment, including a decision not to administer cardiopulmonary resuscitation (CPR) if the person deteriorates rapidly. The decision to not provide CPR does not limit other treatment or care for a patient, but recognises that a person with a serious condition may prefer not to be resuscitated if they have a cardiac arrest.

⁴²³ PCQ, Submission no. 74, p.52

⁴²⁴ Professor Liz Reymond, Submission no. 11, p.10

⁴²⁵ PCQ, *ibid.*, p.52

⁴²⁶ PCQ, *ibid.*, p.51

⁴²⁷ PCQ, *ibid.*, p.52

⁴²⁸ Queensland Ambulance Service (QAS), *Clinical practice guidelines*, Version 1.1 – February 2012, ‘Recognition of life extinct (ROLE) and management of a deceased person’, p.3, accessed 3 April 2013 from http://www.ambulance.qld.gov.au/medical/pdf/10_cpg_other.pdf

⁴²⁹ QAS, *ibid.*, p.3

⁴³⁰ Palliative Care WA Inc., *Palliative caring at home: information for those caring for a person with advanced and terminal illness*, Western Australia edition, January 2012 accessed 3 April 2013 from <http://www.palliativecarewa.asn.au/downloads/Palliative-Care-At-Home-WA.pdf>

The Queensland Ambulance Service clinical practice guidelines indicate that a lawful direction to withhold resuscitation may include a valid Queensland Health ARP that is intended to apply in the circumstances. The guideline advises that if there is any doubt resuscitation should start, and contact made with the patient's medical practitioner.⁴³¹ The committee notes that if a person dies at home, ambulance staff may not have access to a person's ARP.

Palliative Care Queensland advised that ambulance officers do not always acknowledge Advance Health Directives, and will only pronounce/certify death after performing an ECG.⁴³² Professor Reymond told the committee that:

*if we have an expected death at home as part of the palliative care service often the ambulance will come and try to revive them because legally that is what they need to do and if the person is dead they will then contact the police and that person becomes a coroner's case which puts a lot of pressure and complicated grief on family.*⁴³³

Palliative Care Queensland's submission suggested that QAS personnel 'frequently' do not recognise the validity of end of life planning documents, including Advance Health Directives. It said that resuscitation of deceased patients who were expected to die is attempted by QAS "against the wishes of families and palliative care providers", which places additional stress on families.⁴³⁴

Professor Reymond advised the committee that the palliative care service provides a clear written statement that death is expected and that the patient wanted to die at home. "In general, it is always kept on top of the fridge along with the other documentation for life extinct, expected death, how to contact the GP".⁴³⁵ Dr Andrews told the committee that, without an Advance Health Directive an ambulance officer is required to resuscitate; however, some ambulance officers were "quite aware that if (the patient) present(s) at palliative care and an Acute Resuscitation Plan is in place then they have to honour that and the patient is just given comfort measures".⁴³⁶

12.10.3 A person-centred approach

A study of Queensland and Victorian paramedics and their role in palliative care highlighted the tension between a paramedic's primary role to respond to medical emergencies and provide life-saving treatment, and the response required in a palliative care situation.⁴³⁷ The study noted that paramedics receive little training in supporting people at end of life, and it is rarely supported by organisational policies such as clinical guidelines and performance indicators and targets.⁴³⁸

In evidence to the Senate inquiry into palliative care the Amaranth Foundation described how it works with the ambulance service. Amaranth is a non-profit organisation that supports people living at home with advanced terminal conditions. An ambulance protocol is integrated into advance care planning for a patient, and the ambulance service has information about the patient's doctor, that their condition is terminal. With documentation in place and recognised, ambulance officers are able to attend the home if a carer calls with concerns, check on hydration and pain relief and reassure the carer and family that everything needed has been done.⁴³⁹

The committee understands that there is no clinical practice guideline for ambulance officers addressing palliative care situations and that training in a palliative approach across ambulance

⁴³¹ QAS, *ibid.*, p.2

⁴³² PCQ, Submission no. 74, p.52

⁴³³ Professor Liz Reymond, *Public Roundtable Discussion Transcript*, 14 November 2012, pp.10-11

⁴³⁴ PCQ, *ibid.*, p.51

⁴³⁵ Professor Liz Reymond, *ibid.*, p.14

⁴³⁶ Dr Tina Andrews, Palliative Care, Mount Isa Hospital, *Public Hearing Transcript*, 4 February 2013, p.15

⁴³⁷ Lord B, Rechoe K, O'Connor M, Yates P and Service M, 'Paramedics' perceptions of their role in palliative care: Analysis of focus group transcripts', *Journal of Palliative Care*; Spring 2012, 28, 1, pp 36-40, p.39

⁴³⁸ Lord *et al.*, *ibid.*, p.39

⁴³⁹ Amaranth Foundation, evidence to Senate Committee inquiry, *Palliative care in Australia*, p.66

officers may be limited. The committee notes that QAS may be considering changes to ensure that ambulance officers recognise end of life situations and documentation such as the ARP in consultation with some health providers.⁴⁴⁰ The committee suggests that this approach is one that could be applied more broadly.

Recommendation 15 – Palliative care and ambulance services

The committee recommends that the Minister for Police and Community Safety work with the Minister for Health to develop a protocol for ambulance officers if there is an expected death at home or in a residential aged care facility including:

- consultation with Hospital and Health Service palliative care services and ambulance officers
- examination of any legislative barriers to Queensland Ambulance Service (QAS) adopting a palliative approach for patients at home at the end of life
- consideration of wider acceptance by QAS of an Acute Resuscitation Plan or other documentation from a palliative care service or GP
- the provision of appropriate support by the QAS and ambulance officers to patients, carers and families before and after an expected death
- training in a palliative approach for ambulance officers.

12.11 Hospice care

“... it can be difficult on the weekend to get GPs to home visit to issue life extinct or death certificates, as a consequence the police are usually called and an expected death can become a coroner’s case. This is particularly distressing for families.”⁴⁴¹

12.11.1 Capacity and effectiveness

Queensland has a small number of hospices run by non-government organisations which rely significantly on fundraising and donations for their operational costs. All are in the south of Queensland. A number of submissions drew attention to the value of hospice care in providing the ‘right care, in the right place, at the right time’, and the potential to reduce hospital costs.⁴⁴² Eligibility and costs of inpatient hospice care vary due to their variable funding arrangements (see pages 10–11, Chapter 4, for details of existing hospices).

While it is clear to the committee that, given a choice, most people would prefer to stay at home for as long as possible, the reality for some people is that worsening symptoms mean that dying at home is not possible. In those circumstances, a hospice with inpatient beds may be the next preference. A hospice can

... provide holistic care alternatives for the terminally ill who may express a wish to die at home but cannot access sufficient services to achieve this goal. Hospice plays a very important role to provide positive dying experiences and as evidenced by research, instils

⁴⁴⁰ Helen Hoare, Manager, Service Integration, Metro North Brisbane Medicare Local, *Public Roundtable Discussion Transcript*, 14 November 2012, p.14

⁴⁴¹ Professor Liz Reymond, Submission no. 11, p.10

⁴⁴² For example, Palliative care working party Maryborough, Submission no. 20; PCQ, Submission no. 74; and Hopewell Hospice Services Inc., Submission no. 27

*a coping resilience for families and significant others well beyond the bereavement phase.*⁴⁴³

A hospice can provide a specialist nursing care in a home-like environment at the end of life if sufficient supports are not available for the person to die well at home. Hospice “services are ‘resident focussed’ and tailor made according to individual need and wishes”.⁴⁴⁴ For example, if a person wants to die at home, and their condition and symptoms become difficult to manage in the last days of their illness, “... that is where the hospice plays a great role in taking some of the burden away from the family”.⁴⁴⁵

Submissions from hospices stated that their services are efficient. Hopewell Hospice suggested that hospice care is more effective in providing pain relief, based on evidence from Palliative Care Outcomes Collaboration data.⁴⁴⁶

12.11.2 Access to inpatient hospice care

The projected levels of future need for palliative care, along with a focus on increased care in the community, means that more hospice care will be needed. Some people who prefer to remain at home as long as possible will nevertheless prefer to be in an expert care environment at the end of life. Others will have symptoms that are too difficult to manage well at home, and hospice care will be more appropriate.

Several submissions argued that more hospice inpatient beds and increased funding are needed. Some submissions focused on the need for a paediatric hospice (discussed in Chapter 8), while one proposed a new hospice,⁴⁴⁷ existing hospices argued for more funding to meet current needs,⁴⁴⁸ and another advocated the funding of at least two public beds in each existing hospice, and a review of existing funding of hospices to improve equity.⁴⁴⁹

The committee notes that hospices in Queensland rely on fundraising and donations for a significant proportion of their funding. The ways in which hospices have developed in Queensland suggests that there is capacity for models of funding that include philanthropic contributions, for example for capital costs, along with government funding for operational costs and community fundraising. It is important that funding uncertainty in hospices does not impact on the capacity of clinical staff to provide high quality care and ensure patient safety.

⁴⁴³ Toowoomba Hospice Association Inc., Submission no. 21, p.2

⁴⁴⁴ Hopewell Hospice Services Inc., *ibid.*, p.6

⁴⁴⁵ Dr Martin McGahan, *Public Hearing Transcript*, 5 February 2013, p.8

⁴⁴⁶ Hopewell Hospice Services Inc., *ibid.*, p.8

⁴⁴⁷ Palliative care working party Maryborough, *ibid.*

⁴⁴⁸ Ipswich Hospice Care Inc., Submission no. 59; Rev. Dr Ian Mavor, Submission no. 50, p.4

⁴⁴⁹ Hopewell Hospice Services Inc., *ibid.*, p.6 & pp.10–11

Committee comment – Hospices

The committee believes that more hospice beds are needed in Queensland, to provide inpatient care for the dying in a home-like and cost effective setting. Given the current distribution of hospices, there is likely to be a significant need for additional inpatient hospice care outside the south-east of the state. The committee has recommended that the Minister for Health consider the need for more hospice beds in existing hospices, and wider distribution of hospices, as part of assessing population based needs for palliative care.

The committee has also recommended the development of a state-wide strategic plan, and research to develop a population and needs-based model for planning and funding of palliative care services (see Chapter 18). Funding of additional hospice beds and/or hospices should be based on needs, along with assessment of viability of a hospice.

Recommendation 16 – Hospices

The committee recommends that the Minister for Health seek to provide resources for additional hospice beds in existing hospices and/or new hospices, based on an assessment of current and future needs and the viability of potential new hospices.

Chapter 13. Specialist palliative care services

Life is pleasant. Death is peaceful. It's the transition that's troublesome. – Isaac Asimov

13.1 Introduction

This chapter describes the roles of specialist palliative care services, and recommends progressive development and expansion of those services. Of particular importance is the specialist services role in building the capacity of other health and care providers to care for patients using a palliative approach. Specialist palliative care services have an important role in providing complex care for inpatients and people cared for at home and in RACFs, consultancy services to other health providers to support a palliative approach, providing education and training, and undertaking research that can contribute to quality improvement.

Chapter 4 describes the current geographic location of specialist palliative care services. Access to specialist palliative care is not consistent across Queensland. Evidence to the committee about future needs for palliative care, and specific issues for different population groups are discussed in Chapters 7 to 11, and Chapter 12 focusses on palliative care in community settings. Further development of specialist palliative care services has the potential to have a positive impact on most of the issues canvassed in earlier chapters of this report.

13.2 Role of specialist palliative care services

A consistent theme in evidence presented to the committee was the desirability of providing palliative care for as long as possible at home or in a RACF, and reducing the frequency of unwanted and unnecessary admission to hospital via emergency departments. While not all palliative patients are able to be cared for at home, most people would prefer to remain at home for as long as possible. Specialist palliative care services with adequate service capacity are a key component of a system that can provide needs-based and person-centred palliative care.

While the majority of patients who need palliative care may not need specialist palliative care services, it is important that access to those services is based on need. Professor Geoff Mitchell and others report that almost two-thirds of patients with a terminal condition do not receive specialist palliative care.⁴⁵⁰ Many of those patients are well cared for by GPs and other health care providers. Specialist palliative care services may be needed only on a consultation basis to provide advice and support to general practitioners and other primary health care providers. However, some patients whose symptoms are complex or difficult to manage, particularly at the end of life, do need specialist palliative care, either directly, or through specialist consultation and advice with the patient's medical and nursing care providers.

Professor David Currow said that specialist palliative care services should “take responsibility for the whole of the population within a geographic area for each service.” He emphasised that not every person can or should be seen by a specialist palliative care service and suggested that “the onus is on palliative care services to find ways to help referrers identify the people with the most complex needs and offer the additional expertise and support that specialist services can offer”.⁴⁵¹

Submitters and witnesses described the role and functions of specialist palliative care services, and suggested that services should have the capacity to provide a range of services. While not all stakeholders suggested all of the roles for specialist palliative care services listed below, there was a considerable commonality in views that they should provide:

- direct clinical care for people with the most complex needs, including home care with 24-hour access to clinical advice and training and support for home carers

⁴⁵⁰ RACP, Submission no. 25, p.3, citing: Mitchell G *et al.*, ‘Palliative care beyond that for cancer in Australia’

⁴⁵¹ Professor David C. Currow, Submission no. 62, p.7

- consultation, liaison and support for other health providers (in both the private and public sector) to provide palliative care for people with complex needs, including shared care arrangements
- visiting, in-reach or shared care in RACFs
- shared care with other health care providers (in hospitals, hospices, homes and RACFs)
- identification of palliative patients during hospitalisation, prevent crises and re-admission
- loan service for commonly used specialist palliative care equipment
- training of specialist health professionals in palliative care, e.g. registrars, nurse practitioners, and the capacity to employ clinical educators
- continuing education and capacity building for health professionals, including nursing, medical and allied health staff
- research and quality improvement to inform the delivery of best practice palliative care, and
- support and organisation of volunteers who provide respite for carers and social contact for patients.⁴⁵²

The committee recognises that specialist palliative care services vary in the mix of services that they provide, and that not all specialist palliative care services in HHSs will provide services in the same way. While the committee understands the importance of HHS capacity to respond to local needs and circumstances, it considers that this should occur within a state-wide plan that can ensure reasonable and equitable access to services according to need.

The committee endorses the view that public specialist palliative care services, particularly those at higher levels of the Queensland Health Clinical Services Capability Framework, should be developed to have the capacity and be resourced to provide at the least: direct care of patients with complex needs; consultancy services for other health providers including GPs and nurses; 24-hour on-call services for patients cared for at home; equipment loan services (see Chapter 12) visiting or in-reach services to RACFs to support nurses and care staff; and continuing education and capacity building for health professionals. The highest levels of specialist palliative care services should also be involved in teaching of specialist palliative care physicians (this is discussed in Chapter 14).

The capacity to fulfil these roles is consistent with Professor Currow's view that a specialist service should take responsibility for the population in its area. This responsibility does not mean that the service must provide direct specialist palliative care to everyone who needs it in the area, but that a service has a responsibility to ensure that other health providers in the area have the capacity to provide palliative care according to people's needs.

⁴⁵² Note: not all of these submissions included all of the roles of a specialist palliative care service. RACP, Submission no. 25, p.4; Professor David C. Currow, Submission no. 62, p.9; Professor Liz Reymond, Submission no. 11, pp.7, 11 & 13–15; Professor Janet Hardy and Decima Jones, Submission no. 16, p.5; RACP, Submission no. 25; Queensland Health, Submission no. 35

Recommendation 17 – Specialist palliative care services – role and resources

The committee recommends that the Minister for Health work toward ensuring that specialist palliative care services at the highest levels in the Queensland Health Clinical Services Capability Framework are resourced to provide a broad range of services in addition to direct care of patients with complex palliative care needs, particularly:

- consultation services to support other health providers including GPs and nurse practitioners
- visiting or in-reach services to residential aged care facilities
- 24-hour on-call services for patients cared for at home, potentially in collaboration with general practitioners and nurse practitioners
- training and support for home carers, and volunteer coordinators to train and support volunteers to provide in-home respite and carer support
- specialist bereavement counselling
- equipment loan services, and
- continuing education and capacity building for health professionals in palliative approaches.

13.3 Direct clinical care and home care with 24-hour on-call service*13.3.1 Inpatient care*

Direct clinical care of patients with complex needs is a central role of specialist palliative care services. Some specialist services provide inpatient care in a dedicated unit; others provide the care in a variety of wards in a hospital in consultation with clinicians providing care, for example for a patient's terminal malignancy. Some specialist palliative care services that also provide home care or GP shared care, arrange for patients who need inpatient care to be admitted directly to palliative care, rather than via the hospital's emergency department, thus reducing patient stress.

13.3.2 24-hour on-call services

The evidence considered by the committee leads to the view that specialist palliative care in the community, with access to 24-hour on-call clinical support, can enable people to be cared for at home for as long as possible. Family members appreciate the comfort they gain, knowing that they can phone a clinician they know and trust, and evaluation shows that the on-call service decreases inappropriate presentations to emergency departments.⁴⁵³

Submissions and oral evidence have described a variety of models of care. For example, one submission recommended that Level 6 specialist palliative care services in partnership with Medicare Locals, establish after hours palliative care telephone on-call services.⁴⁵⁴ Family members of palliative patients call services "because they are distressed: their family member is in pain." An on-call service needs to be staffed by someone who has expertise in palliative care; it may be medical practitioner or nurse practitioner, "so that we can get the prescription side of it."⁴⁵⁵

The committee has recommended (Recommendation 15 above) that the Minister for Health work toward ensuring that specialist palliative care services are resourced to provide a 24-hour on-call service for palliative patients cared for at home. In locations with sufficient GP capacity, one option is for on-call services to be developed in collaboration with GPs.

⁴⁵³ Professor Liz Reymond, *ibid.*, p.15

⁴⁵⁴ Professor Liz Reymond, *ibid.*, p.18

⁴⁵⁵ Professor Judy Wollin, *Public Roundtable Discussion Transcript*, 14 November 2012, p.5

13.4 Consultation and liaison to support other health providers

13.4.1 Benefits of consultation and liaison services

Palliative Care Queensland submitted that specialist consultancy-liaison services have been shown world-wide to be cost effective, decreasing the average length of stay in acute care beds.⁴⁵⁶ The Australian and New Zealand Society of Palliative Medicine (ANZSPM) submission states that there is “strong evidence that (consultation liaison services) greatly help with improving patient flow, decreasing average length of stay ... in acute care beds and integrating care from hospital to community.”⁴⁵⁷ The Royal Australasian College of General Practitioners (RACGP) also supported adequate resourcing of specialist palliative care services to provide ongoing education and support, consultation services and shared care with GPs.⁴⁵⁸

Queensland Health’s submission noted that the

*The vital role which specialist palliative services have in providing consultation and liaison to other specialist providers as well as a range of generalist health providers including General Practitioners will need to be supported at the HHS level into the future. In this way, the capacity of all providers to deliver person-centred palliative care will be enhanced and access to palliative care will be improved for people who need it.*⁴⁵⁹

The importance of capacity building for non-specialist clinicians was emphasised by Professor Currow:

*Given that specialist palliative care services are, and always will be, referral-based services, specialist services that are only providing clinical care are not fulfilling the role in a way that builds capacity for other clinicians.*⁴⁶⁰

13.4.2 Consultation service capacity and access

It was apparent from evidence to the committee that specialist palliative care consultancy is not sufficiently available to other health providers on a systematic basis,⁴⁶¹ in part because of increasing patient demand, limited resources, and challenges of staff recruitment. It is important that the capacity of specialist palliative care services enables them to provide the level of consultancy and support needed to support other health and care providers using a palliative approach. If non-palliative care health providers, including GPs and other specialists, nurses and allied health staff, and residential aged care staff receive consultancy support, more patients should be able to receive quality palliative care.

Level 5 or 6 services are able to manage highly complex symptoms, and Level 4 services can manage moderately complex symptoms.⁴⁶² These services are assumed to have the clinical expertise to provide consultancy support to other clinicians, although their actual capacity to provide the level of consultancy services needed across Queensland is uncertain. Level 5 and 6 services are located in Brisbane and Townsville, and Level 4 services are located in seven HHSs outside Brisbane. The locations of the three highest service levels shown in a map on page 6 and listed on page 5 in Chapter 4.

⁴⁵⁶ PCQ, Submission no. 74, p.9

⁴⁵⁷ ANZSPM, Submission no. 51, p.9

⁴⁵⁸ RACGP, Submission no. 58, p.3

⁴⁵⁹ Queensland Health, Submission no. 35, p.10

⁴⁶⁰ Professor David C. Currow, Submission no. 62, p.9

⁴⁶¹ e.g. The Karuna Hospice Service Ltd., Submission no. 13, p.2

⁴⁶² See Queensland Health *Clinical Services Capability Framework*, summarised in section 4.2 of this report

13.4.3 Improving capacity of consultation services

The committee has recommended (Recommendation 17 above) that the Minister work toward ensuring that specialist palliative care services are resourced to have the capacity to provide consultation services to other health providers including GPs. The committee considers that specialist palliative care consultation to support a palliative approach in the community is one of the most important roles of specialist palliative care services.

13.4.4 Improving linkages between specialist palliative care and other health providers

Several stakeholders recognised the importance of formalising links between specialist palliative care services with capacity to provide consultancy advice, with generalist services. Professors Yates and Young noted that effective linkages between rural and regional providers and specialist palliative care services are essential for efficient, needs-based care.⁴⁶³ They suggested further research to better understand the current and potential linkages and how an integrated model of care might be delivered based on population needs.⁴⁶⁴ Professor Reymond also suggested further research is needed, with a focus on understanding patterns of patient flow as the basis for telehealth partnerships or linkages between specialist palliative care services and regional and rural generalist services.⁴⁶⁵

If all Queenslanders who need access to the expertise of specialist palliative care services are to be assisted, linkages or partnerships between specialist and non-specialist services will cross HHS boundaries. The most obvious example of the importance of cross-HHS linkages is with the Paediatric Palliative Care Service. As all HHSs do not currently have higher level specialist palliative care services, however, other cross-HHS partnerships are necessary. The committee notes that specialist palliative care services may not currently have the capacity to provide consultation services at the level needed, and that it has recommended that service capacity be improved over time.

Careful planning is needed to ensure that effective linkages of existing and future specialist palliative care services are made with other health providers, including public and private hospitals, medical specialists, general practitioners, primary health care services and RACFs. The committee considers that Queensland Health has an important planning role as system manager to ensure that work is undertaken to identify the most effective arrangements for consultancy with public and private sector health providers. This work will require consultation with clinicians to ensure that consultation service arrangements are effective. The committee also notes the considerable potential to use Queensland Health's videoconference network as a tool to support consultation and capacity building.

Recommendation 18 – Specialist palliative care – formal partnerships with health providers

The committee recommends that the Minister for Health ensure that Queensland Health, as system manager, investigate the most effective framework for formalised links between higher level specialist palliative care services and rural and regional services and GPs for the provision of specialist consultation services, and develop plans for formal partnerships in consultation with clinicians.

⁴⁶³ Professors Patsy Yates and Ross Young, Submission no. 65, p.5

⁴⁶⁴ Professors Patsy Yates and Ross Young, *ibid.*, p.5

⁴⁶⁵ Professor Liz Reymond, Submission no. 11, p.6

13.5 Visiting or in-reach service to residential aged care services

Chapter 12 described some examples of specialist palliative care services working with GPs and RACF staff to support a palliative approach to care in RACFs, including 'in-reach' services, visiting specialist services, 'hospital in the nursing home' services, and support in establishing medication systems for palliative care. The Royal Australasian College of Physicians suggested that "(f)unding to provide the care including specialist palliative care in residential care facilities should be encouraged to ensure this vulnerable older group have care."⁴⁶⁶

The committee considers that a core role of higher level specialist palliative care services is visiting or in-reach services to RACFs, and that specialist palliative care services should be resourced to fulfil this role. The committee has recommended this in Recommendation 17 above.

13.6 Other components of specialist palliative care services

13.6.1 Nurse practitioners – building capacity in palliative care services

The committee heard evidence of the value of nurse practitioners in specialist palliative care services. For example, the Metro South HHS palliative care service in residential aged care facilities, described in section 12.4.3 of the previous chapter, is led by a nurse practitioner. A significant reduction in admission of residents to hospital emergency departments has been achieved, and residents are able to die 'in place'.

The committee considers that efforts to increase the number of specialist palliative care nurse practitioners, particularly in Level 5 and 6 specialist palliative care services, will improve access to services and contribute to quality care in the community. Recommendations to encourage an increase in palliative care nurse practitioners are made in Chapter 14.

13.6.2 Education and training of the health and care workforce

Specialist palliative care services have an important part to play in training and capacity building the health and care workforce. The committee considers this to be a core role of higher level services.

Some of the existing training and resources to develop knowledge and workforce capacity are discussed in Chapter 14.

13.6.3 Volunteers

The important work of trained volunteers in hospices and specialist palliative care services was brought to the committee's attention. In hospices, volunteer roles include in-home support to clients and their caregivers, ancillary tasks such as administration, housekeeping and gardening,⁴⁶⁷

Volunteers can play an important role as in-home respite carers to enable primary carers time for activities outside the home, and in offering general support to the patients and their carers. Volunteers' participation in palliative care can also contribute to improving community understanding about palliative care, death and dying (discussed further in Chapter 16). Volunteers also contribute to keeping services relevant to community needs and cater for diversity.⁴⁶⁸

The committee considers that volunteers could make a significant contribution to more palliative care services, provided they are adequately trained and supported. While the committee supports expansion of volunteer programs in specialist palliative care services, it does not consider that volunteers can replace adequate respite services or specialised staff roles in palliative care.

⁴⁶⁶ Professor Ann Rudden, *Public Hearing Transcript*, 22 August 2012, p.12

⁴⁶⁷ The Karuna Hospice Service Ltd., Submission no. 13, p.3; Toowoomba Hospice Association Inc., Submission no. 21, p.2;

⁴⁶⁸ Hopewell Hospice Services Inc., Submission no. 27, p.5

Chapter 14. Workforce capacity

*... regardless of what level you are working at in this industry you do need a high level of skill. It is not about hand holding ...*⁴⁶⁹

14.1 Introduction

This chapter discusses ways to improve the capacity of the non-specialist health and care workforce to deliver care using a palliative approach, and builds on discussion in Chapter 13 about specialist palliative care services' support for other health and care providers through consultancy services.

The committee heard that an increased demand for services has raised the risk of 'burning out' the palliative care workforce. Funding arrangements also mean that there are impacts on workforce distribution across Queensland and on access to services.⁴⁷⁰ The evidence presented to the committee suggests that effort is needed to improve workforce capacity through:

- increasing the number of medical practitioners who train as specialist palliative care physicians in Queensland
- encouraging more nurses to train as nurse practitioners specialising in palliative care
- promoting greater take-up by health providers of existing education and training opportunities in a palliative approach
- encouraging people from Aboriginal and Torres Strait Islander backgrounds to join the health workforce and ensuring there is adequate training in a palliative approach, and
- ensuring that higher level specialist palliative care services have adequate capacity to provide ongoing consultation, support and training for health providers in a palliative approach, tailored training for home carers and capacity to train and support volunteers (see Chapter 13).

14.2 Palliative care workforce

The health workforce is ageing, consistent with an ageing population. In addition to the need to improve the capacity of health providers to provide care using a palliative approach, and to increase the number of specialist palliative care physicians and nurse practitioners, continued effort is needed to replace retiring health providers. Palliative Care Australia argued that regionalisation of the specialist palliative care workforce by building capacity to provide telehealth, day clinics and advice to generalist health providers is vital.⁴⁷¹

14.3 Specialist palliative care physicians

The committee was advised that there are currently only 0.5 full-time equivalent palliative medicine specialists per 100,000 of population in Australia.⁴⁷² The committee accepts that the current number of specialist palliative care physicians, 22 in Queensland,⁴⁷³ is significantly less than the number required to provide quality palliative care for all Queenslanders. The committee was advised that the accepted benchmark ratio of palliative medicine specialists is between one and 1.5 per 100,000 of population. The Australian and New Zealand Society of Palliative Medicine recommended that the appropriate ratio is one specialist per 100,000 of population which is in line with the position in the United Kingdom.⁴⁷⁴ Palliative Care Australia's recommended ratio of palliative care physicians to

⁴⁶⁹ Kris McAnelly, Australian College of Nurse Practitioners, Queensland Chapter, *Public Roundtable Discussion Transcript*, 28 November 2012, p.9

⁴⁷⁰ PCA, Submission no. 69, p.6

⁴⁷¹ PCA, *ibid.*, p.4–5

⁴⁷² ANZSPM, Submission no. 51, p.6 and RACP, Submission no. 25, p.6

⁴⁷³ PCQ, Submission no. 74, p.39

⁴⁷⁴ ANZSPM, Submission no. 51, pp.6 & 7

population is 1.5 per 100,000 people.⁴⁷⁵ This view was supported by Palliative Care Queensland who suggested that 67 specialist palliative medicine practitioners were needed to service Queensland.⁴⁷⁶ This is approximately 1.4 per 100,000. The committee considers that in order to provide quality palliative care services the number of palliative medicine specialist in Queensland needs to increase.

The committee considers that increasing the number of palliative medicine specialists to a ratio closer to that recommended by ANZSPM would contribute to improved access to palliative care services.

Professor Vora told the committee that building the number of specialists was limited by difficulty in getting funded training positions.⁴⁷⁷ The committee notes that the Senate inquiry reported that the ANZSPM called for Australian Government funding for accredited positions for training in palliative medicine.⁴⁷⁸

The ANZSPM and the RACP recommended that 25 per cent of a palliative medicine physician's time should be funded to provide education and training of junior doctors, other medical specialists and generalists in providing an evidence-based palliative approach and end of life care.⁴⁷⁹ The RACP explained that the concept was outlined by the College of Physicians in the United Kingdom.⁴⁸⁰

The committee has recommended that the Minister work toward expansion of specialist palliative care services so that higher level services (which include a palliative medicine specialist) can undertake a full range of roles, including training of palliative medicine specialists and palliative care nurse practitioners (see Chapter 13).

14.4 Nurse practitioners

Nurse practitioners are a relatively new professional group,⁴⁸¹ who specialise in areas such as nephrology, emergency, palliative care and other specialties. Their scope of practice extends beyond that of nurses and includes prescribing of medication within their scope of practice (see Chapter 12). There are approximately 140 nurse practitioners in Queensland and most work in larger hospitals.⁴⁸²

The Australian College of Nurse Practitioners told the committee there is potentially a significant role for nurse practitioners across Queensland to improve equity of access to specialist palliative care services.⁴⁸³ The Queensland Nurses Union also considers that nurse practitioners are "... a key element in the provision of expert palliative care across metropolitan, rural and remote settings."⁴⁸⁴

Professor Yates told the committee that nurse practitioners had a significant potential role in palliative care in RACFs, provision of timely medication and medication reviews. Professor Yates said that nurse practitioners could work in models of care which provide linkages between a specialist service and the community to make sure that patients do not fall through the cracks. Nurse practitioners:

⁴⁷⁵ PCA, *Palliative Care Service Provision in Australia: A Planning Guide*, 2003, p.25, available at <http://www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceProvision.pdf>

⁴⁷⁶ PCQ, Submission no. 74, p.39

⁴⁷⁷ Professor Rohan Vora, RACP, *Public Hearing Transcript*, 22 August 2012, p.14

⁴⁷⁸ Senate Committee inquiry, *Palliative care in Australia*, p.95

⁴⁷⁹ Australian and New Zealand Society of Palliative Medicine (ANZSPM), Submission no. 51, p.10

⁴⁸⁰ Professor Rohan Vora, *ibid.*, p.12

⁴⁸¹ The first Australian nurse practitioners were endorsed in 2000 and appointed in 2001; the first Queensland nurse practitioner *Delivering the Reforms* was endorsed in 2006. Australian College of Nurse Practitioners, *Australian College of Nurse Practitioners Potted History*, accessed 12 April 2013 from <http://www.acnp.org.au/australian-college-of-nurse-practitioners-potted-history.html>

⁴⁸² Kris McAnelly, *Public Roundtable Discussion Transcript*, 28 November 2012, p.11

⁴⁸³ Kris McAnelly, *ibid.*, p.2

⁴⁸⁴ Queensland Nurses Union, Submission no. 66, p.4

*... would be able to identify those people who might be at risk, for example, of turning up to emergency departments and putting in place whatever is necessary immediately to be able to prevent that. I think nurse practitioners are something for the future that we really should exploit. All of the gaps that they could fill I think are an enormous potential.*⁴⁸⁵

The committee considers that increasing the number of nurse practitioners in specialist palliative care has the potential to significantly improve access to palliative care (including 24-hour care) and improved access to specialist palliative care in regional and rural areas. Nurse practitioners can work in a range of hospital, RACF and community settings, including work with GPs and specialist palliative care services.

The committee understands that there are currently no Queensland Health scholarships for nurses to study the Masters course required to be authorised as a nurse practitioner.⁴⁸⁶ The committee considers that a modest investment of scholarships for nurse practitioners in palliative care would contribute to improved palliative care services, and demonstrate the government's commitment to palliative care and to flexible models of health care delivery.

Recommendation 19 – Nurse practitioner scholarships

The committee recommends that the Minister for Health ensure that Queensland Health nurses are supported to undertake the study required to qualify as a nurse practitioner in palliative care by offering scholarships as soon as possible.

Recommendation 20 – Encouraging nurse practitioners into palliative care

The committee recommends that the Minister for Health consult with stakeholders in nursing and nurse practitioner organisations to identify barriers and enablers to nurses undertaking study to qualify as nurse practitioners, and encouraging nurse practitioners to work in palliative care.

14.5 Training other health providers in a palliative approach

The committee considers that training and capacity building for non-specialist health providers is important so that care is delivered using a palliative approach. A palliative approach aims to improve the quality of life for individuals with a terminal condition and their families, by reducing suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social, and spiritual needs. A palliative approach is not confined to the end stages of an illness, and focusses on active comfort care and a positive approach to reducing a person's symptoms and distress.⁴⁸⁷

A range of professional development and training activities is available to support training and professional development for GPs, other health providers, including nurses and residential aged care workers. Queensland academics and clinicians have made a significant contribution to the professional development and training programs. Education options funded by the Australian

⁴⁸⁵ Professor Patsy Yates, Director, Centre for Palliative Care Research and Education, Queensland University of Technology, *Public Hearing Transcript*, 24 August 2012, p.33

⁴⁸⁶ Queensland Health, *Frequently Asked Questions – Nurse Practitioner*, available at <http://www.health.qld.gov.au/nmog/nurse-practitioner/faqs.asp#edutrain>

⁴⁸⁷ NHMRC, *Guidelines for a Palliative Approach in Residential Aged Care*, pp.3–4

Government include Palliative Care Curriculum for Undergraduates (PCC4U) and a Program of Education in a Palliative Approach (PEPA).

Education for GPs and other health providers is essential to promoting a palliative approach to care and reducing the risk that specialist palliative care services will be over-stretched. There are three main avenues for training in a palliative approach:

- undergraduate education for all health providers
- continuing professional development in a palliative approach
- education and training provided by specialist palliative care services as part of their responsibility in a geographic area.

14.5.1 Undergraduate education in a palliative approach

The Palliative Care Curricula for Undergraduates (PCC4U) has been funded by the Australian Government since 2005. The PCC4U project develops, promotes and provides resources to incorporate palliative care education in undergraduate medical, nursing and allied health courses. The project is led by Professor Patsy Yates of Queensland University of Technology. The PCC4U initiative has engaged with 125 education programs at 38 Australian universities, which represents 59 per cent of all relevant health professional undergraduate programs.⁴⁸⁸

The committee considers that the integration of palliative care education into all health undergraduate health training is essential to the implementation of a palliative approach in generalist health services. The committee notes that undergraduate curricula are often overcrowded, and that this can be a barrier to integrating palliative care into courses. The committee also understands that there may be limited access to practical placements in palliative care, which can operate as a barrier to integrating it into the curriculum.

Recommendation 21 – Palliative care training for undergraduates

The committee recommends that the Minister for Health work with the Centre for Palliative Care Research and Education to encourage Queensland universities to include palliative care in all undergraduate health training courses.

14.5.2 Continuing professional development in a palliative approach

A large part of medical palliative care delivered outside hospitals is provided by GPs. The AMAQ emphasised the importance of education in a palliative approach:

As the main providers of health care information to patients, doctors must be educated about palliative care options and the palliative approach to care, so they are well-equipped to offer a choice of treatment to their patients. This allows patients to make informed choices for themselves and their families.⁴⁸⁹

Care in rural and remote settings would be improved by more palliative care teaching for undergraduates and as part of GP training, and ongoing training for GPs, particularly recognising the increasing number of overseas medical graduates in rural locations, who may not have had exposure to palliative medicine training.⁴⁹⁰

The committee heard differing views about the extent to which Australian Government-funded training opportunities are taken up by GPs and other health providers. The committee notes that

⁴⁸⁸ Professors Patsy Yates and Ross Young, Submission no. 65, p.6

⁴⁸⁹ AMAQ, Submission no. 76, p.2

⁴⁹⁰ ANZSPM, Submission no. 51, p.9

PEPA offers a program for Aboriginal and Torres Strait Islander health workers. Participants in PEPA are able to access support including financial contributions towards backfilling a person who is undertaking training (payable to the employer), and travel for applicants from rural and remote areas.⁴⁹¹

Recommendation 22 – Professional development in a palliative approach

The committee recommends that the Minister for Health:

- consult with medical, nursing and allied health stakeholders to identify barriers and enablers to taking up existing professional development and training, including the Program of Experience in a Palliative Approach (PEPA)
- ensure that Queensland Health and Hospital and Health Services encourage the maximum possible uptake of PEPA training by GPs, nurses and other health providers.

14.5.3 Specialist palliative care services – education and capacity building

Specialist palliative care services need to have the capacity to build and support the other health providers to deliver quality palliative care. The committee has recommended expansion of the capacity and number of specialist palliative care services so that they can fulfil their role to educate and build capacity in the non-specialist health workforce. One palliative care clinician suggested that funding for Level 6 services to employ clinical educators may overcome a major barrier to delivery of quality palliative care. In the absence of funding for educational work, it is provided as resources permit.⁴⁹²

Existing palliative care services have taken a variety of approaches to training and capacity building to date. One service has been involved nationally in developing skills and education, by contributing to development of the specialty of palliative medicine, encouraging GP education and training in palliative care, and developing nursing skills and educating generally.⁴⁹³

Another specialist palliative care service has led training and capacity building in RACFs (see section 12.4.2). Karuna Hospice, a non-government specialist palliative care service offers a seven day workshop on care of the dying. Participants include nurses and other health providers, counsellors, carers and other members of the public.⁴⁹⁴

Professor Geoff Mitchell suggested that developing the capacity of hospital and emergency department staff in a palliative approach would result in improved care and reduce unplanned hospital admissions.⁴⁹⁵ Higher level services could, for example, promote understanding of advance care planning and Advance Health Directives (discussed in Chapter 17), and ensure that the patients are clearly identified on clinical records so, if they present at the emergency department, they can be treated with a palliative approach. The committee notes that there are legal uncertainties that may create difficulties for medical practitioners when a palliative patient presents to an emergency department. Those issues are discussed in Chapter 17.

⁴⁹¹ Program of Experience in the Palliative Approach, *Aboriginal and Torres Strait Islander Health Professionals*, accessed 26 March 2013 from <http://www.pepaeducation.com/health-professionals/aboriginal-and-torres-strait-islander-health-professionals.aspx>

⁴⁹² Professor Liz Reymond, Submission no. 11, p.13

⁴⁹³ Dr Will Cairns, Director, Palliative Care Centre, Townsville Hospital and Health Service, *Public Hearing Transcript*, 5 February 2013, p.2

⁴⁹⁴ The Karuna Hospice Service Ltd., *Education*, available at www.karuna.org.au/education

⁴⁹⁵ Professors Geoff Mitchell and Xavier Gomez-Batiste, Submission no. 52, p.1

Queensland Health has a wide videoconference network in health facilities (see Chapter 15 for a description and map), and the committee considers there is great potential for specialist palliative care services to utilise it to provide education for health providers in rural and regional areas.

The committee heard of difficult situations where people who are terminally ill receive unwanted and burdensome treatment. Clinicians sometimes need to have difficult discussions with patients about the balance of benefit and burden of continuing curative treatments, and palliative or comfort care may not be offered or discussed.

(A)s palliative care medical people, we would recognise that perhaps a lot of patients do not get offered the nil option or perhaps go on having treatments that are perhaps not going to give the amount of benefit that they may think.⁴⁹⁶

The committee recognises that conversations about death and dying are difficult. The committee believes there is scope for training and professional development to support medical practitioners who need to have difficult conversations about prognosis, dying and the relative benefits and burdens of treatment and palliative care. In addition, the committee recognises that palliative care can place an emotional burden on staff, and that it is important that staff have adequate opportunities to de-brief and talk about their care experiences.

Recommendation 23 – Training non-specialists in a palliative approach

The committee recommends that the Minister for Health ensure that expansion of specialist palliative care services include the capacity to provide ongoing training and capacity building of the non-specialist health workforce to provide services using a palliative approach.

14.6 Aboriginal and Torres Strait Islander workforce capacity

14.6.1 Workforce participation

In 2008, a national target was set,⁴⁹⁷ that by 2015 at least 2.6 per cent of public sector employees across all classifications – including health – should be Aboriginal or Torres Strait Islander. In 2008, 2.3 per cent of the Australian population was Aboriginal or Torres Strait Islander, but only 1.6 per cent of the national health workforce was made up of Aboriginal or Torres Strait Islander people.⁴⁹⁸

Improving the participation of Aboriginal and Torres Strait Islander people in tertiary education for health-related disciplines is critical to increasing representation in the health workforce.⁴⁹⁹ The committee notes that progress appears to have been made in this regard. In 2010, 359 Aboriginal or Torres Strait Islander undergraduate students in Queensland were enrolled in health-related courses (2.1 per cent of total undergraduate enrolments). Queensland also had 1,685 Aboriginal or Torres Strait Islander students in 2010 enrolled in health related courses in Vocational Education and Training.⁵⁰⁰ The Australian Indigenous Doctors' Association recently announced that the intake of first-year Aboriginal and Torres Strait Islander medical students in Australian universities has reached a new high of 2.5 per cent, matching the percentage of Australia's Aboriginal and Torres Strait

⁴⁹⁶ Dr Julia Wootton, Clinical Director, Palliative Care, St Vincent's Hospital Brisbane, *Public Roundtable Discussion Transcript*, 14 November 2012, p.7

⁴⁹⁷ In the National Partnership Agreement (NPA) on Indigenous Economic Participation, (COAG, *National Partnership Agreement on Indigenous Economic Participation*, 2009 available at http://www.federalfinancialrelations.gov.au/content/npa/skills/economic_participation/national_partnership.pdf)

⁴⁹⁸ National Aboriginal and Torres Strait Islander Health Council, *A blueprint for action*, p.2

⁴⁹⁹ AIHW, *Aboriginal and Torres Strait Islander Health Performance Framework 2012 Report: Queensland, 2013*, Canberra, p.139, available at <http://www.aihw.gov.au/publication-detail/?id=60129542817>

⁵⁰⁰ AIHW, *ibid.*, p.138

Islander population.⁵⁰¹ The committee believes that the current focus on encouraging Aboriginal and Torres Strait Islander people to join the health workforce should continue.

14.6.2 Supporting enrolled nurses to upgrade qualifications

The committee gained an insight into some of the challenges of ensuring there are sufficient nurses of Aboriginal or Torres Strait Islander background when it met with staff at the Townsville Aboriginal and Islander Health Service. Mrs Ross explained that she and Mrs Marshall, both registered nurses who were previously enrolled nurses, had been trying for about twenty years to encourage young people in their communities to qualify as doctors and nurses. Mrs Ross said: “We need more Aboriginal nurses to work on the floor and to do community stuff. It has just been so difficult. Becoming a registered nurse is not something you get for nothing.” Mrs Ross also said that, despite efforts to support others during their training, “... they fell through the cracks after the second year.”⁵⁰²

The committee believes it is important to fully explore the options to encourage and support Aboriginal and Islander enrolled nurses to upgrade their qualifications to become registered nurses. The need is most pressing in north Queensland, and the committee therefore recommends that the Minister for Health work to explore options for training pathways that would encourage Aboriginal and Torres Strait Islanders to either upgrade from enrolled nurse to registered nurse, or to commence a nursing qualification.

Recommendation 24 – Indigenous nurses – training pathways

The committee recommends that the Minister for Health ensure that work is undertaken to:

- encourage and support Aboriginal and Torres Strait Islander enrolled nurses to upgrade their qualifications to registered nurse
- facilitate the recognition of prior learning for Aboriginal and Torres Strait Islander enrolled nurses who seek to upgrade their qualifications
- develop training pathways to encourage more Aboriginal and Torres Strait Islander people to commence qualifications in nursing.

14.6.3 Palliative care training for enrolled nurses and health workers

One witness highlighted the need to train Aboriginal and Torres Strait Islander health workers in palliative care, grief and bereavement. Mrs Phillips acknowledged the important role of Aboriginal health workers and suggested that there is a good opportunity to include palliative care training in the healthcare training package.⁵⁰³ Witnesses also raised the particular need for debriefing and support for Aboriginal and Torres Strait Islander staff who work in palliative care, particularly in locations where they may have close community and family connections to the person who is dying.

The committee encourages Aboriginal and Torres Strait Islander health workers to apply to undertake PEPA’s program, and recommends that the Minister work to maximise the update of training.

⁵⁰¹ The Australian Indigenous Doctors’ Association and Medical Deans Australia and New Zealand, Media Release ‘Aboriginal and Torres Strait Islander medical student numbers jump’, 21 August 2012, available at <http://www.medicaldeans.org.au/aboriginal-and-torres-strait-islander-medical-student-numbers-jump.html>

⁵⁰² Diana Ross, *Private Roundtable Discussion Transcript*, 5 February 2013, p.7

⁵⁰³ Mona Phillips, *Public Hearing Transcript*, 4 February 2013, p.16

Recommendation 25 – Palliative care training for Aboriginal Health Workers/Practitioners

The committee recommends that the Minister for Health urge all Hospital and Health Services that employ Aboriginal Health Workers and Aboriginal Health Practitioners to consider offering to relevant staff the opportunity to undertake the tailored Program of Experience in a Palliative Approach.

Chapter 15. Telehealth, videoconferencing and eHealth

Telehealth: bringing the collective wisdom of the whole medical system to any patient anywhere [United States Center for Technology Leadership]

15.1 Introduction – use of technology

Recent and new technologies have considerable potential as tools to improve the quality and delivery of palliative care services, as well as other health services. In a geographically dispersed state like Queensland, full use of the modern technology may overcome some of the challenges of distance. Current work nationally to improve the capacity of the broadband network has potential benefits to the use of technology in delivering health care. As well as the potential to improve delivery of quality palliative care services, there is considerable potential for new technologies to be a tool to improve collaboration and co-ordination between services. This is explored in Chapter 23.

In recent years, technology developments have continued at a rapid rate, and future applications and technologies may provide even more potential for use in palliative care and other health care than at present. It is important that technology is not viewed in isolation, but as part of a system of care that presupposes a different way of working, where medical, nursing and allied health providers work in a networked arrangement around the needs of the individual. The technology should be seen as a capability and an enabler.⁵⁰⁴ The complex network of private and public sector and community organisations in providing palliative care emphasises the importance of telehealth that is adaptable to different settings.

15.1.1 Terminology

The terms eHealth and telehealth are used internationally to describe health services delivered via electronic communication and technology:

- **eHealth** is the use of information and communication technologies (ICT) for health. In its broadest sense, eHealth is about improving the flow of information, through electronic means, to support the delivery of health services and the management of health systems,⁵⁰⁵ and
- **telehealth** (or tele-consultation) is the delivery of health services in circumstances involving separation in location and/or time, using ICT.⁵⁰⁶

Telehealth includes transferring voice, data, images and information electronically. Video conferencing is one of the main ways in which telehealth can improve access to services for people in regional and remote areas.⁵⁰⁷

15.1.2 Potential benefits

Some of the potential benefits of using technology to better deliver health services are:

- improved quality of care – supporting uninterrupted, coordinated care across different health care providers
- improved safety for patients – minimising potential to harm patients during care delivery, and
- better access to services – patients able to get healthcare at the right time and the right place irrespective of socio-economic status, location or cultural background
- improved efficiency – achieving desired results with most cost-effective use of resources.⁵⁰⁸

⁵⁰⁴ Goodwin N, 'Telehealth and patient care: Challenges and Solutions – A UK Perspective', Discussion Paper – *Modern Aged Care 2012: Responding to the Challenge Through Technology* Conference, Modern Aged Care 2012, Sydney, 16–18 October 2012, p.2, available at <http://www.testingandevaluation.com/media/6356/853.pdf>

⁵⁰⁵ WHO and International Telecommunication Union, *National eHealth Strategy Toolkit – Overview*, 2012, Geneva, p.1, available at http://www.itu.int/pub/D-STR-E_HEALTH.05-2012

⁵⁰⁶ Loanne M and Wootton R, 'A review of telehealth', *Medical Principles and Practice*, 2001, Vol.10 No.3, pp.163–70

⁵⁰⁷ Department of Broadband, Communications and the Digital Economy, *Health and aged care*, accessed 22 April 2013 from www.nbn.gov.au/nbn-benefits/digital-economy-goals/health-and-aged-care/

15.2 National initiatives

A National eHealth Strategy was agreed by Commonwealth, state and territory health ministers in late 2008. It sets a vision for eHealth enabling a safer, high quality, more equitable and sustainable health system by transforming the way information is used to plan, manage and deliver health care services.⁵⁰⁹ The strategy adopted an incremental and staged approach which would leverage what existed at the time, manage the variations in capacity across the health sector and jurisdictions, and allow scope for change as lessons are learned and technology is developed further.⁵¹⁰

The developing national broadband network (NBN) is expected to facilitate the prompt transfer of data and images, to enable remote diagnosis and treatment. The Australian Government has funded telehealth pilots to demonstrate how the use of the NBN infrastructure affects access to healthcare services, particularly in aged care, palliative care and cancer care and using telehealth in the home.⁵¹¹

The Medicare Telehealth program provides financial incentives to eligible health professionals and aged care services that help patients have a video consultation with a specialist, consultant physician or consultant psychiatrist. The Telehealth program aims to remove barriers to accessing medical services for Australians who have difficulty getting to a specialist or live in rural and remote areas.⁵¹²

15.3 Current and developing use of telehealth in Queensland

15.3.1 Telehealth in Queensland hospitals and health services

Queensland Health has an extensive network of telehealth (videoconference) sites. At June 2009 there were 656 videoconferencing sites across Queensland, most of which are located in hospitals, community health centres, Aboriginal medical services and the offices of the Royal Flying Doctor Service.⁵¹³ They are managed by Queensland Health's Telehealth Services. A map of telehealth sites is on page 92. Two thirds of the videoconference sites were used for clinical activity including patient consultations, case management and follow up. Other uses include clinical simulation training, supervision, mentoring and professional development. A telehealth assessment published in 2011 stated that Queensland is the only state with an explicit consent policy for use of telehealth in public sector health services.⁵¹⁴

Generally, telehealth use in 2011–12 in Queensland Health facilities increased by 27 per cent compared to the previous year. In 2011–12 there were 13,635 occasions of service (see glossary). Private practitioners delivered 2,580 of those occasions of service, using the then new Telehealth Medicare Benefits Schedule items. There were also 2,332 admitted patient Telehealth events recorded in 2011–12.⁵¹⁵

⁵⁰⁸ National eHealth Transition Authority, *Making Sense of eHealth Collaboration: A guide to getting started*, 2012, Sydney, p.15, available at http://www.nehta.gov.au/component/docman/doc_download/1605-making-sense-of-ehealth-collaboration-a-guide-to-getting-started

⁵⁰⁹ Australian Health Ministers' Conference, *National E-Health Strategy Summary*, 2008, p.5, available at http://www.ahmac.gov.au/cms_documents/National%20E-Health%20Strategy.pdf

⁵¹⁰ Australian Health Ministers' Conference, *ibid.*, 'Foreword'

⁵¹¹ Department of Broadband, Communications and the Digital Economy, *NBN-enabled Telehealth Pilots Program*, accessed 22 April 2013 from www.nbn.gov.au/nbn-benefits/government-initiatives/health-and-aged-care/

⁵¹² Department of Human Services, *Telehealth for health professionals*, accessed 23 April 2013 from <http://www.medicareaustralia.gov.au/provider/incentives/telehealth/information-for-health-professionals.jsp>

⁵¹³ UniQuest Pty Ltd, *Telehealth Assessment Final Report*, 2011, UniQuest, Brisbane, p.14, available at [http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/EC471B2E09EE7370CA2578A4001092BE/\\$File/UniQuest%20Telehealth%20Assessment%20Report%20.pdf](http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/EC471B2E09EE7370CA2578A4001092BE/$File/UniQuest%20Telehealth%20Assessment%20Report%20.pdf)

⁵¹⁴ UniQuest Pty Ltd, *ibid.*, p.28

⁵¹⁵ Queensland Health, *Annual Report 2011–12*, 2012, Brisbane, pp.10–11, available at http://www.health.qld.gov.au/about_qhealth/annual-report/11-12/default.asp

The committee understands that telehealth has not been used extensively for palliative care consultations to date, but considers there is significant potential to improve access to clinical care and specialist advice through its use.

15.3.2 Examples of telehealth use

The committee was informed of examples of the current and developing use of telehealth in Queensland, in both public and private sector health services. While most of the examples below are not in palliative care, they illustrate some of the potential benefits of telehealth.

- **Townsville Cancer Centre.** Videoconferencing is used for rural patients to access medical oncology services. Patients are allocated an appointment time in routine medical oncology clinics and 'attend' by videoconference. Urgent videoconference consultations can be arranged if needed. The patient and their support person are joined by a chemotherapy competent nurse, senior medical officer, and allied health providers. Patients are examined by the attending doctors during consultations. The benefits of videoconferencing include consultations and urgent medical care in a patient's home town; treatment closer to a patient's home (particularly people who live in a remote area and may travel to Mount Isa for treatment); reduced travel for patients; and high levels of patient satisfaction.⁵¹⁶
- **Intensive Care Unit monitoring – Townsville to Mount Isa.** Using a combination of videoconferencing, remote vital sign monitoring, delivery of pathology and digital X-ray images allows experience ICU specialists in Townsville to support clinicians and patients in Mount Isa.⁵¹⁷
- **Geriatric telehealth service.** Since May 2009, a geriatrician at Caloundra Hospital has provided telehealth consultations to Maryborough Hospital. A similar service is provided by Cairns Base Hospital to aged care services in Innisfail, Mareeba and Cairns.⁵¹⁸
- **Geriatrician services to patients at Toowoomba Base Hospital** are provided by videoconference by a specialist at Princess Alexandra Hospital. Without the use of technology the specialist would need to travel 125 km to Toowoomba.⁵¹⁹
- **St Vincent's Private Hospital Brisbane,** has established a Telehealth Education and Support Project to further develop telehealth expertise in general practitioners and general practice registrars in rural southeast Queensland. Telehealth services are available in palliative care, geriatrics, neurosciences, pain management, psychogeriatrics and rehabilitation. The services can be bulk billed and affirm the GP's central role in the co-ordination of patient care if the GP and patient participate together, while providing learning and development for the GP.⁵²⁰
- **A specialist palliative care pilot project at Ipswich** which is supporting GPs with palliative patients through case conferences will explore the use of telehealth for conferences.⁵²¹
- **Hopewell Hospice** intends in future to provide telehealth Skype counselling and bereavement follow-up support to families.⁵²²
- **Hong Kong Hospital Authority** community palliative care service uses phones to link care workers at the person's home with specialists, the patient's clinical record, and if relevant a videoconference by phone with the patient and care worker. Medication changes can be authorised and advice about care provided by phone.⁵²³

⁵¹⁶ Sabesan S and Brennan S 'Tele Oncology for Cancer Care in Rural Australia, Telemedicine Techniques and Applications', in Graschew G and Rakowsky S (ed.), *Telemedicine Techniques and Applications*, 2011, Intech, pp.290–5, available at <http://www.intechopen.com/books/telemedicine-techniques-and-applications>

⁵¹⁷ UniQuest Pty Ltd, *ibid.*, p.14

⁵¹⁸ UniQuest Pty Ltd, *ibid.*, p.14

⁵¹⁹ Cordwell T, Cox N and Gray L, 'The ageing population accessing services with the help of Technology', *Proceedings of the 10th National Rural Health Conference*, Gregory G (ed.), Cairns, 17–20 May 2009, National Rural Health Alliance, Canberra available at http://10thnrhc.ruralhealth.org.au/papers/docs/Cordwell_Tiffany_D1.pdf

⁵²⁰ St Vincent's Hospital Brisbane, *Telehealth*, accessed 8 March 2012 from <http://svphb.org.au/our-services/telehealth/>

⁵²¹ Professors Geoff Mitchell and Xavier Gomez-Batiste, Submission no. 52, p.8

⁵²² Deirdre Hanna, Submission no. 49, p.2

⁵²³ Tam Shepherd, *Public Hearing Transcript*, 22 August 2013, p.24

15.4 Telehealth and palliative care

15.4.1 Patient consultations

Telehealth could have a positive impact on palliative care services in rural and remote areas. It can link people and their health care providers with specialist palliative care advice. Face-to-face consultation with a local health professional is important but a video consultation with a palliative care team or other specialist, facilitated and supported by local health professionals, can provide additional expertise and support.⁵²⁴

Submissions to the committee highlighted the potential to address some barriers of distance and workforce shortage in rural areas by development of telehealth models and video-consultations.⁵²⁵ Anglicare submitted that technology and telehealth could provide timely support and advice for clients and carers, to monitor clients, and to improve rural access specialist palliative care.⁵²⁶ Mrs Quilliam, Queensland Kids described the positive effect of telehealth for a family caring for their child in a remote area. The family had 24-hour access to medical and nursing support and the Paediatric Palliative Care Service advised local staff about the care needs of the child. The parents felt that their child had 'a very good death' because of the telehealth access to support.⁵²⁷

Cairns and Hinterland HHS submission proposed that telehealth could be used in a regional specialist palliative care service to deliver day clinics and provide on-call 24-hour specialist consultation advice to primary health providers. Equitable distribution of regional specialist palliative care staff would contribute to solving the problems of geography.⁵²⁸ As described above, videoconferencing is already being used in the region to provide geriatrician services.

Dr McGahan reinforced the potential use of telehealth for consultation with a patient who is remote, and noted that a "...person at the remote area has to have the practical skills to carry out that advice. Most of the patient skills needed are at a nursing level. Most remote communities do have nursing ...".⁵²⁹ The need for a clinician to be present with the patient at the remote site was also emphasised by Mount Isa clinicians who told the committee that to date videoconference palliative care consultations at remote locations had not included a health provider.⁵³⁰ If a nurse or doctor is present they can assist both the palliative care specialist staff and the patient to understand care and symptoms and their management. A clinician could also examine the patient so that more information is available to the palliative care specialist.⁵³¹ The committee has recommended (Recommendation 18, Chapter 13) that formalised links between specialist palliative care services and rural and regional services and GPs be investigated and implemented. The committee believes that appropriate planning can support improvements in telehealth arrangements for patient consultations, including the logistics of ensuring that a clinician is available for patient videoconference consultations.

15.4.2 Training, development and clinical supervision

There was a consistent view from palliative care stakeholders that telehealth has considerable potential in education, professional development and clinical supervision in palliative care. Blue Care highlighted the positive role telehealth could play in the education and up-skilling of health

⁵²⁴ National Rural Health Alliance and Palliative Care Australia, *Palliative care in rural and remote areas*, p.2

⁵²⁵ Submissions no. 5, 6, 39 (p.10), 63 and 72

⁵²⁶ Anglicare Southern Queensland, Submission no. 72

⁵²⁷ Gabrielle Quilliam, *Public Hearing Transcript*, 22 August 2012, p.19

⁵²⁸ PCA, Submission no. 69, pp.4–5

⁵²⁹ Dr Martin McGahan, private capacity, *Public Hearing Transcript*, 5 February 2013, p.6

⁵³⁰ Dr Tina Andrews, *Public Hearing Transcript*, Mount Isa, 4 February 2013, p.4

⁵³¹ Dr Marjad Page, *Public Hearing Transcript*, Mount Isa, 4 February 2013, p.4

practitioners in palliative care.⁵³² Sharyn Hopkins, Queensland Nursing Council suggested that clinical supervision arrangements by videoconference could form part of incentives for nurse practitioners and nurses to work in rural areas. Supervision arrangements would mean "... that there is not that professional isolation for clinicians".⁵³³ Professor Vora suggested that, with formalised links between specialist palliative care services and regional areas, telehealth creates opportunities for skill development, as well as remote supervision of advanced specialist trainees, who could go to remote areas and still have proper remote supervision.⁵³⁴ The Queensland Nurses Union also suggested that videoconference has the potential in providing support for generalist health care providers delivering care using a palliative approach.⁵³⁵

Recommendation 26 – Videoconferencing

The committee recommends that the Minister for Health ensure that Queensland Health:

- consult with Hospital and Health Services and their specialist palliative care services to identify any barriers to increased use of the existing videoconference network for palliative care, and
- promote the use of videoconferencing in palliative care and consider developing incentives to promote greater use of videoconferencing for patient consultations, consultation with health providers to provide advice, build capacity and to provide training and professional development in palliative care.

15.5 Electronic health records

There is a range of electronic health records available in different settings, including the national personally controlled electronic health record, systems developed for GP practices, (public hospital systems (e.g. an integrated electronic medical record (ieMR) being implemented in nine hospital sites commencing in 2013) and palliative care service clinical records systems (e.g. Brisbane Metro South Palliative Care Clinical Information System) and many others.

15.5.1 National electronic health record

In 2012, the Australian Government launched a personally controlled electronic health record (PCEHR). The national PCEHR is intended to be a secure network of systems enabling access to consolidated and summarised health information drawn from multiple sources across the health sector, including data from Medicare, the Organ Donor Register and Childhood Immunisation Register. Healthcare organisations can register to participate in the PCEHR and authorise doctors, nurses and other appropriate users within their organisation to view patient records through the secure online provider portal. Individuals can apply to create a PCEHR.⁵³⁶ As the PCEHR is not yet universal there are limitations on its utility.

15.5.2 Off-site access to electronic clinical records

The committee believes that future needs for palliative care can be met only by building the capacity of non-specialist health care providers so that more palliative care can be delivered at home and in

⁵³² For example, Blue Care and UnitingCare Health, Submission no. 24, p.18; Sharyn Hopkins, Queensland Nurses Union, *Public Roundtable Discussion Transcript*, 28 November 2012, p.11; Professor Rohan Vora, RACP, *Public Hearing Transcript*, 22 August 2012, p.12

⁵³³ Sharyn Hopkins, *ibid.*, p.11

⁵³⁴ Professor Rohan Vora, *ibid.*, p.12

⁵³⁵ Sharyn Hopkins, *ibid.*, p.11

⁵³⁶ DOHA, *Personally controlled electronic health records*, accessed 4 March 2013 from www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/content/pcehr

RACFs. Non-specialist health providers will need the support of an expanded network of specialist palliative care services to deliver care using a palliative approach. They will need the capacity to work collaboratively to deliver person-centred care, and access to electronic clinical and care records in all care locations will be a key component of delivering quality care.

In March 2012, the Queensland Clinical Senate recommended that the system manager (Queensland Health) ensure that a system is developed to allow for mobile/off-site clinician access to electronic healthcare records, and access between Hospital and Health Services.⁵³⁷

At a service level, the Brisbane Metro South Palliative Care has a Clinical Information Management System (PCCIMS) – a web-based information system which allows for real time access to palliative patient information. Clinical records for patients of the palliative care service can be accessed remotely by all members of the care team, including during home visits. Access to current clinical information helps to improve patient safety and quality of care across all environments of care. The PCCIMS also promotes transition to home care and ensures accessible, accurate and contemporaneous patient information. PCCIMS also supports Brisbane Metro South's 24-hour telephone on-call service which is staffed by rostered nurses and doctors. Evaluation has shown that it also decreases inappropriate presentations to emergency departments.⁵³⁸

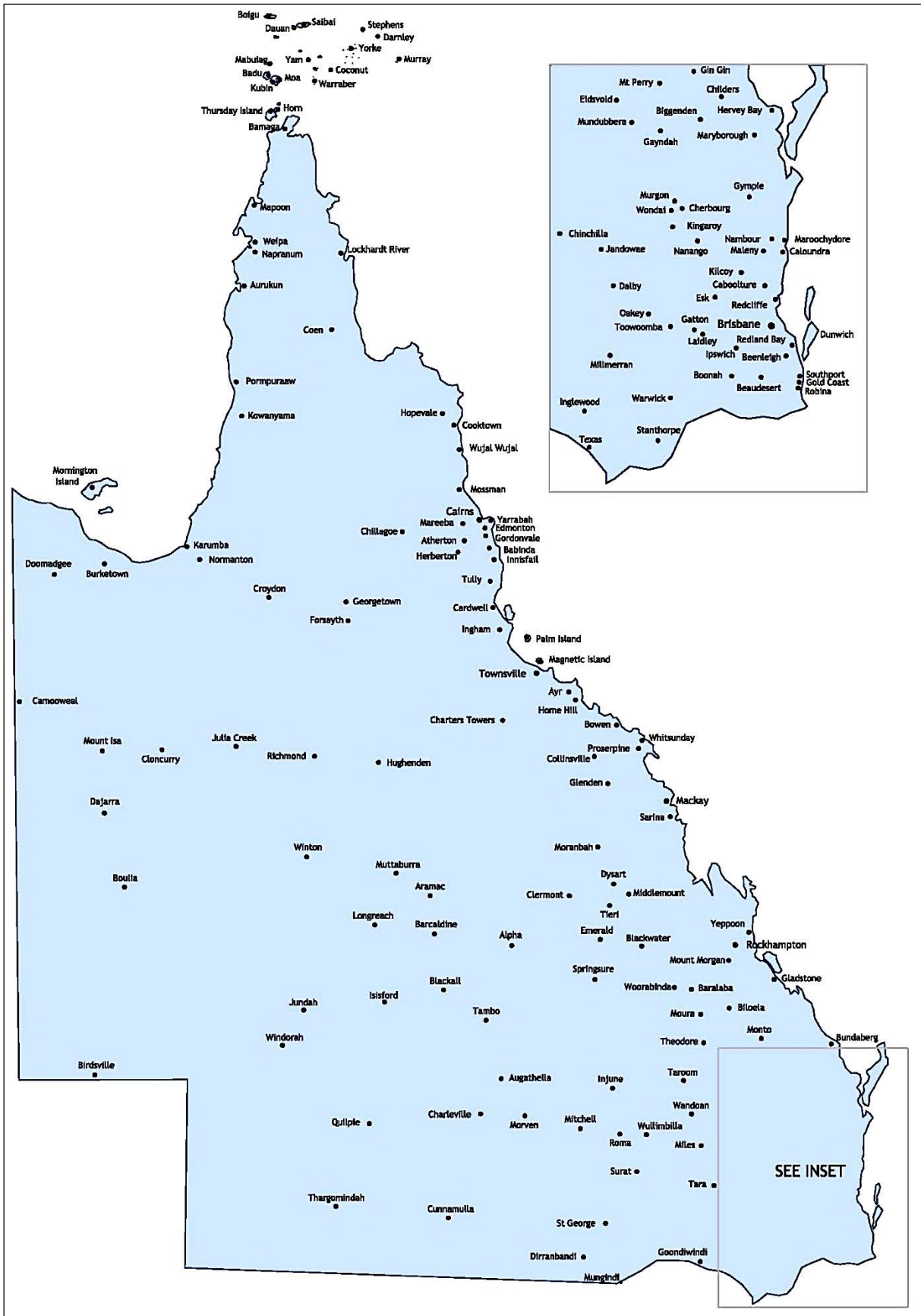
Recommendation 27 – Telehealth and eHealth

The committee recommends that the Minister for Health continue to support the development of national telehealth and eHealth initiatives that are suitable for use by all palliative health and care providers across public, community and private settings.

⁵³⁷ Queensland Clinical Senate, *Final Report and Recommendations – Implementing the Queensland Health Purchasing Framework 2012/13: how clinicians can make a difference*, 15–16 March 2012, Parliament House, Queensland, p.5, available at http://www.health.qld.gov.au/qldclinicalsenate/docs/rprec_15-16mch12.pdf

⁵³⁸ Professor Liz Reymond, Submission no. 11, p.5

Map 2: Queensland Health Statewide Telehealth Services – Videoconference site map ⁵³⁹



539 Available at: http://www.health.qld.gov.au/telehealth/docs/vc_site_map.pdf

Chapter 16. Awareness and education – palliative care, dying and death

*Look at how we prepare for birth. Look at how we prepare for marriage.
Why do we not prepare in the same way for death?*⁵⁴⁰

16.1 Introduction

The need to improve awareness and understanding of palliative care and of death as part of life is well recognised in the palliative care community and by Governments. The committee believes that a community conversation about the normality of dying is important. Greater awareness and open discussion about dying, death and palliative care can facilitate planning and enable people to make choices about where and how they want to be treated as they approach the end of life. In the committee's view, improving public education is also necessary to encourage advance care planning and increase the use of Advance Health Directives, which are discussed in Chapter 17.

The importance of being able to think and talk about the end of life, and to engage with emotionally difficult issues, was highlighted by Dr Cairns who told the committee:

*It is quite challenging for many people to talk about their mortality, but I think if we have a culture where that is something that people can address candidly and openly, albeit often with a lot of emotion attached to it.*⁵⁴¹

16.2 National Palliative Care Strategy – improving awareness

The National Palliative Care Strategy was endorsed by the Australian Health Ministers' Conference in 2010 to guide palliative care policy development and service delivery. Improving awareness and understanding is one area for action. Consistent with the views articulated by submitters and witnesses, the strategy states that better understanding will support improved access to palliative care services.

*There is a need to significantly enhance the understanding of dying, death, grief, bereavement and loss in Australia, including in health professionals and carers, to support better access to appropriate, timely services across the end of life continuum.*⁵⁴²

The two goals in the National Strategy to improve understanding are:

- to significantly improve the appreciation of dying and death as a normal part of life, and
- to enhance community and professional awareness of the scope and benefits of timely and appropriate access to palliative care services.

The strategy sets out actions that will be undertaken to contribute to achievement of those goals:

- develop a comprehensive, evidence based, multi-modal and targeted national public awareness strategy to promote death as a normal part of living and promote available services and options
- promote collaborative integration of health and human services and increase the visibility of end of life issues, palliative care and roles and responsibilities
- provide mechanisms to ensure palliative care providers provide culturally appropriate care
- support national roll out of Advance Care Planning and address any barriers
- encourage integration of palliative care training within all health undergraduate and relevant post-graduate curricula.⁵⁴³

⁵⁴⁰ Catherine Mickel, *Public Roundtable Discussion Transcript*, 14 November 2012, p.9

⁵⁴¹ Dr Will Cairns, *Public Hearing Transcript*, 5 February 2013, p.2

⁵⁴² DOHA, *National Palliative Care Strategy 2010*, p.8

⁵⁴³ DOHA, *ibid.*, p.11

16.3 Current public awareness activities

Palliative Care Australia (PCA) currently produces brochures to promote awareness including simple information about palliative care, understanding grief, diabetes and palliative care, pain management, and patient rights and responsibilities. Some brochures are available in other languages. A major awareness raising activity is national Palliative Care Week, organised by PCA, Palliative Care Queensland (PCQ) and equivalent bodies in states and territories. In addition, the *CareSearch* website,⁵⁴⁴ funded by the Australian Government, has a range of information about aspects of palliative care.

The role of PCQ includes improving awareness and understanding of palliative care in the community.⁵⁴⁵ In recent years PCQ has produced a DVD, *Understanding Palliative Care*, co-hosted the Australian Palliative Care Conference 2012, in Cairns and hosted two community forums called 'Your Death Your Choice'.⁵⁴⁶ Other public awareness activities are undertaken on a modest scale by various organisations.

16.4 Improving community awareness

The committee heard from submitters and stakeholders that more work is needed to improve understanding, and to promote advance care planning and the uptake of Advance Health Directives. Palliative Care Queensland recognised that raising awareness of end of life issues is challenging.⁵⁴⁷ It reinforced the view that awareness of death and dying promotes acceptance and uptake of advance care planning and choice particularly about where a person may wish to die and the type of care they choose.⁵⁴⁸

*End of life issues and end of life decision making are concepts that all Queenslanders must confront at some point in the trajectory of their own lives. Whether we are caring for an ageing parent, supporting a chronically ill relative, or even confronting a life-limiting illness of our own, it is vital that at some point, we all contemplate and plan for our own end of life.*⁵⁴⁹

Submitters and witnesses who work in palliative care reflected the approach of the *National Palliative Care Strategy* and highlighted the importance of normalising death and dying as a part of living, in a culturally sensitive way. For example, we are generally reluctant to talk about death and dying until there is a crisis.⁵⁵⁰

There are a number of misconceptions about palliative care, in particular that it is only for cancer patients. Dr Andrews said there "should be more community awareness that palliative care is not just cancer care".⁵⁵¹ While palliative care originated from the care of people with cancer, increased incidence of chronic disease and longer survival times means that approximately 40 per cent of people who receive palliative care in Queensland are now those with chronic disease.⁵⁵² Another common misconception is that palliative care is relevant only in the last days or weeks of life. Ms Kay, Mount Isa Hospital explained that when Aboriginal and Torres Strait Islander people hear the word 'palliative', they think they are dying straight away and suggested "... if we just raise awareness as to what services are provided and where they can get the services, I think it will help".⁵⁵³

⁵⁴⁴ CareSearch, *CareSearch palliative care knowledge network*

⁵⁴⁵ PCQ, Submission no. 74, p. 4

⁵⁴⁶ PCQ, *ibid.*, p. 33

⁵⁴⁷ PCQ, *ibid.*, p. 48

⁵⁴⁸ PCA, Submission no. 69, pp.3–4

⁵⁴⁹ PCQ, *ibid.*, p. 48

⁵⁵⁰ Wesley Mission Brisbane, Submission no. 26, p.6

⁵⁵¹ Dr Tina Andrews, *Public Hearing Transcript*, 4 February 2013, p.17

⁵⁵² Queensland Health, Submission no.35, p.2

⁵⁵³ Gemma Kay, Social Worker, Mount Isa Hospital, *Public Hearing Transcript*, 4 February 2013, p.17

16.5 Future directions

A state-wide community awareness campaign was recommended by PCQ to educate Queenslanders about palliative care, death and dying in order to promote effective decision making at end of life.⁵⁵⁴ Queensland COTA said that increased funding is needed for a community awareness campaign on palliative care and end of life care that includes encouraging the use of advance care directives.⁵⁵⁵

One witness noted the efforts to normalise discussion of organ donation while arguing for normalisation of discussion about dying and palliative care.⁵⁵⁶ Another suggested that we need to provide the tools that people need to have conversations about dying.⁵⁵⁷ The committee heard that material to explain palliative care and the services available should be in Aboriginal languages.⁵⁵⁸ Another witness suggested that the National Indigenous TV network should be used to promote awareness about palliative care to Indigenous people. “ ... I see things on health and I think it is brilliant. But we need some airtime on radio and TV really stepping that up.”⁵⁵⁹

While the available printed and web-based information about palliative care is useful, the committee considers that to make a significant impact on community awareness and understanding a broad multi-faceted approach is required, as the *National Palliative Care Strategy* contemplates.

Recommendation 28 – National public awareness campaign

The committee recommends that the Minister for Health work with his Commonwealth, state and territory ministerial counterparts to actively promote implementation of a national public awareness campaign as soon as practical to increase public understanding of:

- death as a normal part of living
- awareness of palliative care options, and
- the importance of advance care planning to facilitate choices about care.

16.6 Health providers and referral to palliative care

The level and timing of referral to palliative care by doctors can be constrained by their awareness and values about curative treatment. Blue Care and UnitingCare Health said that the inability to cure a patient’s condition affected referrals and cited research to suggest that “a sense of failure by medical practitioners has been seen as a major reason for lack of referral earlier in the disease trajectory”.⁵⁶⁰

Dr Cairns said that we “cannot escape that reality that every one of us is going to die and that there will come a time when efforts at life prolongation become futile or actually burdensome to the patient”.⁵⁶¹ While advances in medical treatment and better management of incurable diseases are publicly welcomed, those advances can be a challenge to the recognition that death and dying are normal and universal. Dr Wootton said:

⁵⁵⁴ PCQ, Submission no. 74, p.15

⁵⁵⁵ Mark Tucker-Evans, *Public Hearing Transcript*, 24 August 2012, p.1

⁵⁵⁶ Helen Hoare, *Public Roundtable Discussion Transcript*, 14 November 2012, p.16

⁵⁵⁷ Glenys Webby, *Public Roundtable Discussion Transcript*, 14 November 2012, p.9

⁵⁵⁸ Dr Marjad Page, *Public Hearing Transcript*, 4 February 2013, pp.10–11

⁵⁵⁹ Diana Ross, *Private Roundtable Discussion Transcript*, 5 February 2013, p.14

⁵⁶⁰ Blue Care and UnitingCare Health, Submission no. 24, p.16

⁵⁶¹ Dr Will Cairns, *Public Hearing Transcript*, 5 February 2013, p.2

*Over the last 50 years we have almost come to deny death because people with really serious illnesses can go on for so long. So I think there is a need for a change in the culture in terms of doctors...*⁵⁶²

The committee was told of the impact of delayed referral to palliative care. A young child receiving treatment for multiple life-limiting conditions from a number of specialists was referred to the Paediatric Palliative Care Service (PPCS). Pain management and other care led to a substantial change in the child's quality of life; unable to sit at the time of referral she was able to crawl and stand with support after a few days. Her parents asked for referral to the palliative care service after learning about it from other parents.

*Our daughter's consultant physicians were unaware that (she) was eligible for PPCS services as they thought it was only an end-of-life service. The benefit of early referral to PPCS is that it can maximise the quality of life for children before they reach end stage and families have the chance to form trusted relationships before they reach the unthinkable end-stage.*⁵⁶³

It is not difficult to see that early referral may also benefit adults as well as children with life-limiting conditions.

Dr Wootton commented that the concept of palliative care is often introduced late in a patient's disease trajectory. It is often perceived 'you finish X before you go on to Y', that is, palliative care is relevant only after curative treatment has finished.⁵⁶⁴ Early referral to specialist palliative care services would not necessarily lead to large increases in patient numbers for those specialist services. If specialist palliative care services have sufficient capacity to support GPs and other health providers through consultation services or shared care, patients could continue to receive care in the home or community, but receive the benefits of specialist advice, for example about management of complex pain.

Health providers who have had access to professional development about a palliative approach can be expected to lead to greater awareness and timely referral to specialist palliative care services. The committee has recommended in Chapter 14 that the Minister for Health consult with stakeholders to identify and address any barriers to participation in professional development about palliative care.

⁵⁶² Dr Julia Wootton, *Public Roundtable Discussion Transcript*, 14 November 2012, p. 7

⁵⁶³ Name suppressed, Submission no.33, p.5

⁵⁶⁴ Dr Julia Wootton, *ibid.*, p.3

Chapter 17. Advance care planning and Advance Health Directives

Patients consider five factors to be important for a 'good death': managing symptoms, avoiding prolongation of dying, achieving a sense of control, relieving burdens placed on the family, and the strengthening of relationships.⁵⁶⁵

17.1 Introduction and terminology

The terms *advance care planning*, *advance health directive* and other terms are sometimes used interchangeably, which can be confusing, particularly as different terms are used for legal advance directives in other states. The terms used in this report are:

- **advance care planning** is a process of discussion with a person about their future health care preferences. It may result in a written plan, which may change over time as a person's circumstances alter and they make ongoing decisions about their health care. Advance care planning is most commonly done when a person is diagnosed with a terminal condition, has life-limiting chronic conditions or moves into a residential aged care facility.
- **advance health directive (AHD)** is a document made under the *Powers of Attorney Act 1998* to give directions about future health care; it applies when a person no longer has capacity to make their own decisions. It may include appointing an 'attorney' to make decisions about a health matter if the directions in the advance health directive prove inadequate. A person may decide to prepare an AHD while young and healthy, may be prompted to do so after diagnosis, and/or after discussion of advance care planning.

It is also possible to make an enduring power of attorney (EPOA) under the *Powers of Attorney Act 1998* to appoint a person to make decisions about personal matters (which includes health decisions) or financial matters.⁵⁶⁶

If a person's capacity to make health decisions is impaired and there is no statutory AHD or EPOA, then a person who is a 'statutory health attorney' under the *Powers of Attorney Act 1998* may make decisions about health care. Broadly, the person's spouse, the person who cares for them, or an adult relative or friend may make health decisions on behalf of the person whose decision making capacity is impaired.⁵⁶⁷

17.2 Advance care planning

Submitters, witnesses and expert organisations supported advance care planning and argued that it has a variety of benefits. Advance care planning is possible only if patients, families and health providers are able to discuss emotionally difficult issues about prognosis and dying. As discussed in the previous chapter, an increase in advance care planning could be facilitated by a public awareness campaign that normalises death and dying as part of life that we prepare for, as we prepare for other life transitions.

Several submitters and witnesses talked about the difficulties for both patients and health providers as "... it is very hard for people to contemplate their own death. We are programmed to live, not to die, and you need that relationship to be able to go there."⁵⁶⁸

⁵⁶⁵ Detering *et al.*, 'The impact of advance care planning on end of life care in elderly patients'

⁵⁶⁶ see *Powers of Attorney Act 1998*, available at <http://www.legislation.qld.gov.au/LEGISLTN/CURRENT/P/PowersofAttA98.pdf>

⁵⁶⁷ see section 63, *Powers of Attorney Act 1998*, *ibid.*

⁵⁶⁸ Professor Liz Reymond, *Public Roundtable Discussion Transcript*, 14 November 2012, p.5

17.3 Patient centred care

There is greater potential to deliver person-centred palliative care if a patient's preferences and directions about their treatment and care are understood by the treating health providers, and are grounded in an understanding of their medical condition. Palliative Care Queensland stated that "Every Australian and every Queenslanders should be given the opportunity to participate in a (advance care planning) discussion around future health care choices."⁵⁶⁹ Planning ahead for our own end of life is far more likely to result in our wishes and goals being acknowledged, respected and implemented.

A *Medical Journal of Australia* editorial described advance care planning as a way to ensure that care is patient-centred:

*...by ensuring that their consent to treatment is fully informed, by understanding their goals and values that are relevant to their current or future treatment, and by identifying their wished regarding treatment if they become seriously ill and can no longer decide or communicate what they want.*⁵⁷⁰

The Australian Medical Association *Position Statement on the Role of the Medical Practitioner in End of Life Care*:

*strongly promotes advance care planning as a process of supporting patient self-determination, including the development of advance directives and the identification of surrogate decision-makers...*⁵⁷¹

17.4 Benefits of advance care planning

*Thinking about death is quite difficult for a start and conversations around this subject are really quite complicated. It's about dignity, it's about burdens, it's about outcomes. And I cannot predict what is going to drive you as a patient; you need to tell me. For some people, dignity is most important. But for some people, there is dignity in suffering. This is all about personal choice.*⁵⁷²

Advance care planning has been shown to improve end of life care for elderly patients, improve patient and family satisfaction and reduce stress, anxiety and depression in surviving relatives.⁵⁷³ These outcomes were reported in a randomised controlled trial of advance care planning in 309 medical inpatients aged 80 or more. The trial incorporated elements of advance care planning that had been identified by other studies as crucial to success: trained facilitators (in this study, nurses); patient centred discussions; family involvement in discussions; correctly filed documentation; and systematic education of doctors.⁵⁷⁴

There is sometimes a tension for health providers and others between, on the one hand, curative treatment and the 'fight' to overcome a disease such as cancer, and on the other hand, acceptance of some people's wish near the end of life to decline curative treatment, have pain and other symptoms managed, and not prolong the process of dying. Chapter 12 includes discussion of this tension for ambulance staff when called to a palliative patient, or a death at home. Similar tensions

⁵⁶⁹ PCQ, Submission no. 74, p.48

⁵⁷⁰ Silvester W and Detering K, 'Advance care planning and end-of-life care', *MJA*, October 2011, Vol.195, No.8, pp.435–6, p.435

⁵⁷¹ Australian Medical Association, available at <https://ama.com.au/position-statement/role-medical-practitioner-end-life-care-2007>

⁵⁷² McMahon N, 'Death on her terms', *The Age*, 6 May 2013, accessed 6 May 2013 from <http://www.theage.com.au/national/death-on-her-terms-20130504-2j017.html>

⁵⁷³ Detering *et al.*, 'The impact of advance care planning on end of life care in elderly patients', p.7

⁵⁷⁴ Detering *et al.*, 'ibid.', p.5

arise in other health settings, including hospital emergency departments where attempts may be made to resuscitate and treat a palliative patient whose wish may be to let nature take its course and not prolong dying.

Palliative Care Queensland said that

*... expensive needless treatments can be avoided if the wishes of the patient are known and a surrogate decision maker has been appointed and involved in the advance care planning processes. Patients can be made aware of palliative care as a treatment option much earlier, and if health professionals are prepared to work together to achieve quality of life rather than promote futile attempts at cure that are often invasive and expensive, patients and families have a far better chance at achieving quality of life, including dying in the setting of their choice.*⁵⁷⁵

Professor Reymond reinforced the view that more advance care planning will lead to fewer futile and expensive procedures on frail and dying patients, and more compassionate, patient-centred care.⁵⁷⁶ Residents of RACFs who deteriorate quickly, if their wishes are not known, may be transferred by ambulance to an acute hospital, which may not be their wish. An advance direction can avoid unwanted transfers.⁵⁷⁷

17.5 Facilitating more advance care planning

The committee heard that advance care planning needs time for discussion between a patient and health provider, and family or friends “(It) is important in ... palliative care ... that people are able to have the conversations with doctors and health professionals and others that they need to and we are not well equipped ... to do that.”⁵⁷⁸ Advance care planning discussions may need to be revisited as a person’s condition changes, or as their views about their diagnosis and end of life evolve. “... advance care planning is actually an ongoing fluid sort of issue ... the goal posts keep changing all the time and so must the advance care planning. I think it is about ongoing conversations.”⁵⁷⁹ In an acute hospital setting, there is sometimes not as much time for discussion as is needed.

Dr Deuble said:

*... we are talking about one of the most major events in our life—that is, we are all mortal and one day we will die—and we want to choose the environment, how that will be, and what we expect from our family and from the health system.*⁵⁸⁰

Ms Webby emphasised that people may need support to plan for their future health care, and health providers needs time for those discussions. “... the real issue is about how people are supported to make those choices ... we do not have a good process that is commonly accepted across the industry, or funded for that matter, to support people to do advance care planning. I think that is the crux of this part of the problem.”⁵⁸¹

Dr Blackwell of Palliative Care Australia said that he is “... seeing the immense impact, just in residential aged care, of families and people sitting down and saying what they want for the future. I think it is about ... providing the time and the expertise into the whole process as something that is an automatic, routine part of the way we do business in health.”⁵⁸²

575 PCQ, Submission no. 74, p.15

576 Professor Liz Reymond, Submission no. 11, p.13

577 Wesley Mission Brisbane, Submission no. 26, p.4

578 Glenys Webby, *Public Roundtable Discussion Transcript*, 14 November 2012, p.10

579 Professor Liz Reymond, *Public Roundtable Discussion Transcript*, 14 November 2012, p.9

580 Dr Mark Deuble, *Public Hearing Transcript*, 24 August 2012, p.30

581 Glenys Webby, *ibid.*, p.8

582 Dr Scott Blackwell, *Public Hearing Transcript*, 22 August 2012, p.5

A widely used Australian approach to supporting advance care planning is *Respecting Patient Choices*, which was developed in Victoria. It provides a co-ordinated, systematic approach to patient centred advance care planning by trained facilitators. The program is designed to train and support health professionals to discuss end of life preferences with patients and their families in a sensitive and compassionate way.

Over the last three years *Respecting Patient Choices* has been implemented in health services in the West Moreton and Darling Downs area. Ms Dooley told the committee that it has been very effective, and that evidence supports the view that if advance care planning is offered early, informed choices are made about health care.⁵⁸³

A goal of the National Palliative Care Strategy is to support the national roll out of advance care planning, as well as increase public and health professional awareness of palliative care.⁵⁸⁴ The committee supports the recommendation of the Senate Committee inquiry that the Australian Government fund a national public awareness campaign around advance care planning and directives, starting immediately, and expanding once a process of national harmonisation of advance care planning regulation has been undertaken.⁵⁸⁵

The committee also supports the Senate Committee inquiry recommendation that the Australian Government increase the level of funding for the *Respecting Patient Choices* program to support development of training providers in several jurisdictions, significantly expanding the reach of the program in the aged care sector.

Recommendation 29 – Public awareness – advance care planning

The committee recommends that the Minister for Health inform the Commonwealth Minister for Health that the committee supports the Recommendations 35 and 37 in the Senate Community References Committee report, *Palliative care in Australia*, that:

- the Australian Government fund a national public awareness campaign around advance care planning and directives, starting immediately, and expanding once a process of national harmonisation of advance care planning regulation has been undertaken
- the Australian Government increase the level of funding for the Respecting Patient Choices program to support development of training providers in several jurisdictions, significantly expanding the reach of the program in the aged care sector.

17.6 Advance Health Directives – legislation

As noted above, a discussion about advance care planning may lead to documentation of an Advance Health Directive. However, some people initiate an AHD when they are younger and healthy, based on their views about future health care, should they not have the capacity to make their own decisions.

The Queensland *Powers of Attorney Act 1998* provides for creation of an AHD. To create an AHD some advance care planning is necessary so that directions for future care can be made. If a person is healthy at the time, their AHD might provide fairly general directions based on values and preferences. Alternatively a person with known chronic disease or a terminal diagnosis might provide specific directions relevant to their treatment for known conditions. An AHD must be signed in the

583 Kerri-Anne Dooley, *Public Hearing Transcript*, 22 August 2012, p.8

584 Commonwealth of Australia, *Supporting Australians to Live Well at the End of Life: National Palliative Care Strategy*, 2010, available at <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-strategy.htm>

585 Senate Committee inquiry, *Palliative care in Australia*, p. 199

presence of a doctor, and the doctor must confirm that the person has the capacity to make the directive. The form encourages the person to discuss their proposed advance directions with their general practitioner or a specialist doctor who knows their medical history and views.

17.7 Benefits of advance health directives

The benefits of AHDs are similar to the benefits of advance care planning. The AMAQ supported advance care planning and the use of AHDs. It described the benefits as providing patients with a means of informing health care decisions, including the withholding and/or withdrawing of life-sustaining measures, in the event of losing decision-making capacity in the future. An AHD also benefits surrogate decision-makers, doctors and other health providers by reducing the stress of trying to make treatment decisions that reflect the person's wishes. The AMAQ noted that AHDs can also advance the rational use of health resources and encourage the provision of care in the most appropriate environment.⁵⁸⁶

Professor Mitchell described a demonstration project where a senior nurse identifies residents of residential aged care facilities (RACF) who have been admitted to hospital, assists with the development of an AHD, and helps RACF staff understand how the AHD can be implemented. The use of AHDs among nursing home residents has increased, and anecdotally, significant acute hospital costs have been avoided.⁵⁸⁷ As noted above, advance care planning is believed to reduce health costs while maximising the potential to provide care in the way that people prefer.

17.8 National laws – advance health directives

Some form of advance health directive or advance care directive is used in all Australian states and territories. A *National Framework for Advance Care Directives* was published in 2011⁵⁸⁸, setting out a broad policy framework for states and territories to work toward harmonisation of legislation. The National Framework noted that Australia's Health Ministers recognised the need for a standardised national format for advance health directives, and had decided that the challenges of divergent laws and the concerns about use and application of advance directives was best addressed by a national policy framework. The National Framework recommends the use of common terminology, contains principles for ethical practice when advance directives are applied, and sets out best practice standards for consistent policy and legislation.⁵⁸⁹

Palliative Care Australia has argued for the need for a single common legislative requirement for Australia.⁵⁹⁰ Palliative Care Queensland also suggested that nationally consistent legislation be developed, which would provide an assurance that AHDs, including a substitute decision maker's role, would be valid and respected in all Australian jurisdictions.⁵⁹¹ A number of submitters and witnesses supported nationally consistent legislation about advance health decisions and highlighted the advantages of a national approach. With national consistency, people could feel confident that their preferences about future health care would apply if they were interstate, as well as in Queensland. Health and care organisations that operate in more than one state could develop consistent policy and training, and doctors and other health who practice in more than one state could have confidence in following an advance health directive of a patient from interstate without

586 AMAQ, Submission no. 67, p.4

587 Professor Geoff Mitchell, Professor General Practice and Palliative Care, Ipswich Campus, University of Queensland, *Public Hearing Transcript*, 24 August 2012, p.40

588 AHMAC, *A National Framework for Advance Care Directives*, September 2011, Clinical, Technical and Ethical Principal Committee, accessed 11 January 2013 from http://www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.pdf

589 AHMAC, *ibid.*, p.9

590 PCA, *Advance Care Planning*, accessed 26 April 2013 from <http://www.palliativecare.org.au/Portals/46/PCA%20Advance%20Care%20Planning%20Position%20Statement.pdf>

591 PCQ, Submission no. 74, p.49

fear of inadvertently contravening the law.⁵⁹² The AMAQ supported the work of the Australian Health Ministers' Advisory Council in setting out the principles that should underpin a nationally consistent approach.⁵⁹³

*The Queensland Government should work with other state governments to further integrate and provide mutual recognition of advance care directives from all states and territories. Ideally, this integration and recognition will result in nationally consistent legislation which will provide certainty for both patients and doctors.*⁵⁹⁴

17.9 Review of laws about advance health directive

The legislation about advance health directives was considered as one component of the Queensland Law Reform Commission (QLRC) review of the *Guardianship and Administration Act 2000* and the *Powers of Attorney Act 1998*. The QLRC report, *A review of Queensland's Guardianship Laws*, published 2010 made over 300 recommendations about the guardianship laws.

Those QLRC recommendations that were relevant to advance health directives were referred to the former Health and Disabilities Committee of the last Parliament. The former committee held a public forum and received submissions, but did not complete its inquiry before the dissolution of the Queensland Parliament in February 2012.

The committee notes that complex legal, ethical and clinical issues underpin discussion of AHDs and the extent to which they are followed. The committee acknowledges that there are unresolved issues in Queensland's system of AHDs, and that there are diverse views on some of those issues.

Recommendation 30 – Advance Health Directives

The committee recommends that, given the uncertainties about current Queensland law governing advance health directives, the Government consider referring to the Health and Community Services Committee an inquiry into the law that applies to Advance Health Directives in Queensland.

17.10 Increasing the use of Advance Health Directives

17.10.1 Doctors' role

The committee received commentary from the Australian Medical Association about practical arrangements for completion of an AHD. Medical practitioners have a role in assisting patients to develop an AHD by discussing treatment issues related to future health care options. Such discussions are an accepted part of good clinical care and the doctor-patient relationship.⁵⁹⁵ The AMAQ told the committee that doctors have a responsibility to ensure that patients who make an AHD: are competent to do so; are fully informed and have had an adequate opportunity to receive advice on health care options relevant to their current and possible future conditions; understand the information, including medical concepts and terminology in the advance health directive; have the capacity to understand the decisions they have made; and are acting voluntarily (as best as the medical practitioner can determine this).⁵⁹⁶

592 Blue Care and UnitingCare Health, Submission no. 24, p.19; PCQ, *ibid.*, p.49; AMAQ, *ibid.*, p.5

593 AMAQ, *ibid.*, p.5

594 AMAQ, *ibid.*, p.5

595 AMAQ, *ibid.*, p.5

596 AMAQ, *ibid.*, p.5

The AMAQ said remuneration for assisting with an AHD is inadequate, and suggested that the Queensland Government should advocate for changes to Medicare Benefits Schedule (MBS) explanatory notes to clarify which existing MBS items can be used for consultations about development of an AHD.⁵⁹⁷ The AMAQ said:

*... there is currently no financial assistance to patients for such discussions. AMA Queensland believes it is important for the Medicare Benefits Schedule (MBS) to provide patients with a rebate for the time that it takes for medical practitioners to undertake consultations to assist patients in preparing AHDs.*⁵⁹⁸

Recommendation 31 – Advance Health Directives and doctors

The committee recommends that the Minister for Health write to the Commonwealth Minister for Health to seek clarification of which Medicare Benefits Schedule items doctors may use for consultations to support a patient to complete an advance health directive.

Some stakeholders suggested that general practitioners could have a positive role in awareness raising, noting that more progress might be made “... if the AMA at the policy level and GPs at the coalface were to take a more pro-active role in making all patients of legal age aware of the value of giving consideration to taking out an AHD.”⁵⁹⁹ The committee notes the evidence from the AMAQ that there is limited financial incentive for this to occur.

17.11 AHDs in electronic health records

Implementation of advance care plans and AHDs is dependent on health and care providers having access to a person’s AHD. The committee was told that an AHD “... is only as good as the health professionals knowing that they ... exist. Often in health care people are not aware that [a] person has a health directive”.⁶⁰⁰ The committee was told that older people have expressed fears that “their health professional may not be aware of their preferences for treatment.”⁶⁰¹

A number of submitters advocated attaching care plans and AHDs to electronic health records so that all in the health care team has access to the information.⁶⁰² The potential of electronic health records as a tool in improving co-ordination in health care is discussed in the next chapter.

17.12 Public education and advance health directives

The previous chapter discussed public awareness and education about dying and death as a normal part of life. To increase the level of advance care planning and the creation of AHDs requires recognition of mortality – not a usual part of our public discourse. The challenge is to, “... get the community to understand that these are important things—that it is useful to put down your wishes to let your loved ones know what you want...”⁶⁰³ The committee believes that public awareness measures that focus on the benefits of advance care planning and AHDs could be an accessible approach to public education. This approach was broadly supported by submitters and witnesses.

Some public education is undertaken, but it does not appear to have a broad impact, possibly because as a community we do not see it as relevant to them. “As has been said, many people are

597 AMAQ, *ibid.*, p.5

598 AMAQ, *ibid.*, p.5

599 Dying With Dignity, Submission no. 12, p.3

600 Professor Patsy Yates, *Public Briefing Transcript*, 20 June 2012, p.5

601 COTA, Submission no. 48, p.2

602 For example, PCQ, Submission no. 74, p.11; COTA Queensland, *ibid.*, p.2

603 Professor Patsy Yates, *ibid.*, p.5

reluctant to fill out those forms because it makes them think about the end.”⁶⁰⁴ The committee was told of a recent publication prepared by COTA Queensland, Health Consumers Queensland and others to provide simple information, broken into easily understood language:

*It really is about trying to make this as easily understood as possible, that in fact it is a positive thing to do rather than a negative thing ... written from a consumer perspective rather than from a service provider perspective, getting the legal jargon out of it and making it user friendly. It is also about utilising people at the local level to actually talk about it.*⁶⁰⁵

604 Mark Tucker-Evans, *Public Hearing Transcript*, 24 August 2012, p.3

605 Mark Tucker-Evans, *ibid.*, p.3

Chapter 18. Resourcing and delivering needs-based and person-centred palliative care in Queensland

*... if we have a community that truly wishes to care for its dying people and frail and aged people well, then we have a community to be proud of.*⁶⁰⁶

18.1 Funding palliative care

18.1.1 Recent funding arrangements and levels

Funding arrangements for palliative care have changed as national health reforms are fully implemented. Queensland Health advised that, in 2010-11, an estimated \$51.3 million was spent on admitted public hospital subacute palliative care in Queensland.⁶⁰⁷ Queensland Health provided a summary of palliative care funding by HHS for 2010-11 (see Table 7). In its 2010 Budget the Australian Government allocated \$1.62 billion to provide 1,316 subacute care beds (or bed equivalents) across the states and territories. Palliative Care Australia noted that the 'bundling' of palliative care into the 'subacute' funding category does not lead to improved palliative care service provision and access, and there was no evidence that Queensland had allocated any additional subacute funding to palliative care services.⁶⁰⁸

Table 7: Summary of palliative care funding for 2010–2011

Hospital and Health Service	Total Funds
Cairns and Hinterland	\$6,351,615.00
Cape York	\$114,964.00
Central QLD	\$3,431,512.00
Central West	\$148,603.00
Children's Health QLD	\$365,245.00
Darling Downs	\$3,200,395.00
Gold Coast	\$7,309,504.00
Mackay	\$1,336,163.00
Mater Public Hospital s	\$1,615,144.00
Metro North	\$12,884,329.00
Metro South	\$9,785,241.00
North West	\$354,074.00
South West	\$355,385.00
Sunshine Coast	\$5,320,947.00
Townsville	\$4,465,028.00
West Moreton*	\$3,068,281.00
Wide Bay	\$3,066,292.00
Torres Strait Northern Peninsula	\$47,328.00
St Vincent's Hospital **	\$5,893,612.18
Community Services Purchasing	\$27,720.00
Total	\$69,141,382.18

* In 2010–2011 Darling Downs and West Moreton were a single District

** QLD Health has an existing contract with St Vincent's which includes this funding for the provision of palliative care

Source: Extracted from Queensland Health, Submission no. 35, Appendix 2 (more detail is available in the submission)

⁶⁰⁶ Dr Mark Deuble, *Public Hearing Transcript*, 24 August 2012, p.26

⁶⁰⁷ Queensland Health, Submission no. 35, p.5

⁶⁰⁸ PCA, Submission no. 69, p.6

In 2011-12 Commonwealth and State funding provided to Queensland Health for non-hospital-based palliative care services was approximately \$17 million.⁶⁰⁹ This was in addition to hospital-based services.

The Australian & New Zealand Society of Palliative Medicine (ANZSPM) stated in its submission that the National Partnership Agreement on Hospital and Health Workforce Reform (NPA HHWR) provided additional funding for subacute care and had been “the major source of growth funding for palliative care in Australia over the last few years”.⁶¹⁰ Under the NPA HHWR, Commonwealth funding for subacute care was provided in 2008-09 for the states and territories to expand service provision by five per cent annually over the period to 2012–13.⁶¹¹ Queensland’s implementation plan for the NPA focussed on enhancing the capacity of rehabilitation services. No additional funding was directed to palliative care under the implementation plan, although a review of the palliative care service system was to be undertaken. The ANZSPM drew attention to the “relative paucity of funding” that had been allocated to palliative care under the NPA HHWR.⁶¹²

The Minister for Health advised the committee in August 2012 that funding to be allocated through Queensland Health in 2012–2013 for palliative care, predominantly from Queensland Government sources, would increase by about 12.9 per cent in recognition of the increasing demand for palliative care services.⁶¹³ Queensland Health noted that through the National Partnership Agreement on Improving Public Hospital Services (NPA IPHS) palliative care services in both hospital and community settings will be increased by 44 beds or bed equivalents by 30 June 2014 at a cost of \$47 million.⁶¹⁴ The planned additional funding includes:

- 10 new palliative care beds at QEII Hospital, opened in early 2012
- 10 new palliative care beds at Redlands
- funding for general sub-acute beds using existing infrastructure in many regional and rural hospitals, some of which will support palliative care.
- an initial \$1.5 million per annum to various non-government organisations for the provision of palliative care in the community.
- additional funding to six Hospital and Health Services to purchase additional palliative care services from non-government providers.⁶¹⁵

18.1.2 Adequacy of funding

Adequate funding for palliative care is essential as patients at the end-of-life are “among the most vulnerable members of our society”,⁶¹⁶ and quality end-of-life care should be the aim of every health care system. As discussed in section 6.3, current needs for palliative care are not met by existing service levels, and access to palliative care is not equitable across Queensland.

While submitters recognised the funding contribution of both the Queensland and Australian governments for palliative care, evidence to the committee supported the view that palliative care in Queensland is currently under resourced. Palliative Care Queensland noted that services have “evolved erratically and continue to operate in a patchwork fashion”.⁶¹⁷ The Australian Healthcare

⁶⁰⁹ Queensland Health, *ibid.*, p.5

⁶¹⁰ ANZSPM, Submission no. 51, p.5

⁶¹¹ COAG, *National Partnership Agreement on Hospital and Health Workforce Reform, 2012*, Schedule C, p.23, available at http://www.federalfinancialrelations.gov.au/content/npa/health_payments/workforce-reform/national_partnership.pdf

⁶¹² ANZSPM, Submission no. 51, p.5

⁶¹³ Hon. Lawrence Springborg MP, *Public Hearing Transcript*, 22 August 2012, p.26

⁶¹⁴ Queensland Health, *ibid.*, p.6

⁶¹⁵ Queensland Health, *ibid.*, p.6

⁶¹⁶ ANZSPM, *ibid.*, p.4

⁶¹⁷ PCQ, Submission no. 74, p.12

and Hospital Association described the system as ‘haphazard’.⁶¹⁸ There is a view that current funding mechanisms are based on palliative care trajectories of people with cancer, which are no longer appropriate. Professors Yates and Young advised the committee that funding and funding arrangements to date had developed in an ‘ad hoc’ manner’.⁶¹⁹ Palliative Care Queensland also drew attention to the differences in funding for palliative care across regions as well as the differences in designated beds across districts, noting the inequities that have developed.⁶²⁰

Under the pressure of growing need for palliative care services, it seems that quality has been maintained while services have been rationed and access has been restricted.⁶²¹ Rationing means that arbitrary and unsuitable limits are placed on the provision of palliative care services, such as the three month limit of life expectancy that many submissions mentioned in relation to Palliative Care Program funding. This time limit on funding assumes that a patient will only need palliative care in the last three months of life and that the expected time until death can be readily established for that patient.⁶²²

Other restrictions on service due to funding levels noted by PCQ were that Gladstone would soon lose its after-hours palliative care service, and the Gold Coast had closed four beds and stopped taking referrals from non-cancer patients.⁶²³ Increasing and unmet demand for palliative care services leads to patients presenting at emergency departments and admitted to acute care beds. This is more expensive for the health care system and inappropriate to patient needs.⁶²⁴

The October 2012 report of the Senate Inquiry into palliative care in Australia commented that it was difficult to establish if services were being appropriately provided given the lack of data on funding and expenditure on palliative care at a state level.⁶²⁵

18.1.3 Access to specialist palliative care

As described in Chapter 6, there is currently insufficient capacity in Queensland’s palliative care services to meet current needs. Access to specialist palliative care, or to specialist palliative care advice to other health providers who are providing primary palliative care, is patchy.

Palliative Care Queensland submitted that some regions have little or no access to specialist palliative care services. Inequitable access to specialist services is in part due to rationing of stretched services. For example, some public sector specialist palliative care services only accept patients with three months or less life expectancy, although it is difficult to estimate a person’s prognosis.⁶²⁶ As noted earlier in section 7.4, such a time limit bears little relation to actual end-of-life trajectories or what might be episodic needs for palliative care. Submissions indicated ‘frustrations’ about time limits attached to funding for community service providers and concerns about the insufficient funds to adequately meet client needs.⁶²⁷ Six months was noted as a more appropriate average for length of stay in palliative care.⁶²⁸

⁶¹⁸ Australian Health and Hospitals Association, Submission no. 22, p.3

⁶¹⁹ Professors Patsy Yates and Ross Young, Submission no. 65, p.1

⁶²⁰ Professor Rohan Vora, PCQ, *Public Hearing Transcript*, 22 August 2012, p.7

⁶²¹ PCA, Submission no. 69, p.10. See also Professor Rohan Vora, Submission no. 73 and Professor Janet Hardy and Decima Jones, Submission no. 16, p.4

⁶²² PCQ, Submission no. 74, p.32

⁶²³ Professor Rohan Vora, *ibid.*, p.7

⁶²⁴ Professor Rohan Vora, *ibid.*, p.7

⁶²⁵ Senate Committee inquiry, *Palliative care in Australia*, 50–53

⁶²⁶ Professor Janet Hardy and Decima Jones, *ibid.*, p.7

⁶²⁷ Metro North Hospital and Health Service, Submission no. 45, p.2 and St Vincent’s Hospital Brisbane, Submission no. 44, p.5

⁶²⁸ US Home Hospice program, quoted in Professor Rohan Vora, Submission no. 73, p.6

Other palliative care services will not accept patients who are still having treatment such as chemotherapy,⁶²⁹ despite increasing recognition that ‘palliative chemotherapy’ can be provided to enhance quality of life rather than to cure malignancy. A number of submissions called for a review of the level of funding and its administration.

Specialist palliative care services have also responded to high levels of demand by, for example, not providing after hours care or home visits, or restricting services according to patient diagnosis.⁶³⁰

18.2 Needs-based funding arrangement

18.2.1 A state-wide palliative care strategy

Work is needed to progressively improve the capacity of the health system and care services to provide high quality palliative care to all of those who could benefit from it. The need for palliative care is expected to increase significantly in future (see Chapter 7) and it is necessary to identify how to provide quality services in the most effective way. For some people, palliative care will be best delivered by a general practitioner or other primary health service, for others, the best care will be provided by a specialist palliative care service or by a local primary health care service with input from a specialist palliative care consultant by videoconference. The diversity of approaches to delivering good quality palliative care requires a coherent state-wide framework to ensure the best use of resources, equitable access and high standards of care that meet people’s needs.

The National Palliative Care Strategy provides a framework that gives direction to palliative care policy, planning and service development, toward common and agreed goals (see section 1.6). Most other Australian jurisdictions have a strategy or policy framework to translate the broad national strategy to a state-wide guide for the development of policy, planning, funding and service development.

The committee considers that a state-wide palliative care strategy is needed to guide work to increase the capacity of the service system to meet current and future needs. A state-wide strategy could articulate high level goals and expectations for the development, standard and co-ordination of care.

The need for a state-wide framework was a common theme in submissions and oral evidence to the committee. Palliative Care Australia stated:

*A significant gap in efficiency is the absence of strategic planning in palliative care with clear timelines for improvement at state and territory level. ...This makes planning for service provision, including funding and evaluation of service outcomes, extremely problematic, adding to inefficiency and ad hoc decision making.*⁶³¹

A Queensland strategy could set out a well-informed approach to the provision, planning, funding and delivery of palliative care services, to provide clear aims and guidance to HHSs and private and non-government providers of palliative care. As one stakeholder put it: “.... we need that common purpose and understanding and some form of document that we can all subscribe to across the continuum of care”.⁶³² A whole of system approach is required in a strategic plan, to provide a framework that can bring together care by specialist palliative care services, non-specialist health providers, hospitals, general practitioners and other community based care.

⁶²⁹ Professor Janet Hardy and Decima Jones, *ibid.*, p.7

⁶³⁰ Professor Rohan Vora, *ibid.*, p.4 and Professor Janet Hardy and Decima Jones, *ibid.*, p.4

⁶³¹ PCA, *ibid.*, p.11

⁶³² Glenys Webby, *Public Roundtable Discussion Transcript*, 14 November 2012, p.15

Recommendation 32 – State-wide palliative care strategy

The committee recommends that the Minister for Health ensure that a state-wide palliative care strategy is developed as soon as possible to guide the development of palliative care planning, funding, development of specialist services, and improvement in the capacity of primary health and generalist health and care services to implement a palliative approach to care.

Recommendation 33 – State-wide palliative care strategy – key elements

The committee recommends that the Minister for Health ensure that the state-wide palliative care strategy:

- is aligned with the National Palliative Care Strategy
- supports population and needs-based allocation of funding to maximise equity in the delivery of palliative care services, including equitable access for people with chronic conditions as well as those with cancer
- includes a staged approach to expansion of specialist palliative care services based on an assessment of palliative care needs for Queensland
- has a whole of system focus that promotes collaboration between acute hospital, specialist care and palliative care in the community
- acknowledges that most people would prefer home-based palliative care, and promotes the delivery of palliative care in the home when it is the patient's preference and it is possible to provide high quality care at home
- emphasises palliative care that is person-centred, based on needs, and allows patients and families to make choices about their care and where care is provided
- recognises the importance of bereavement care and support for family members, and significant others
- promotes case management approaches that use integrated electronic health records which link with other care providers and general practitioners
- aligns with the Clinical Services Capability Framework that applies to Hospital and Health Services and licensed private health facilities
- promotes planning by Hospital and Health Services to provide palliative care services in a range of settings including specialist consultation and liaison services to support palliative care in the home and residential aged care facilities
- promotes integrated care that includes advance care planning, and
- includes timeframes for implementation of the main components of the strategy.

18.2.2 Mapping existing palliative care services

There was a strong view from those working in palliative care that more specialist services are needed. One submission recommended that, depending on population needs and geographical constraints, every Hospital and Health Service should have a Level 5 or Level 6 specialist palliative care service.⁶³³ Public sector palliative care services self-assess their level in the Clinical Services Capability Framework (CSCF), which is described in Chapter 4 (sections 4.2.1–4.2.2) of this report. To assist in planning for future development and funding of palliative care services, self-assessed CSCF levels need to be externally reviewed, to accurately map existing levels of service provision.

⁶³³ Professor Liz Reymond, Submission no. 11, p.6

Recommendation 34 – Clinical Services Capability Framework – review of service levels

The committee recommends that the Minister for Health ensure that the self-assessed levels of palliative care services in the Clinical Services Capability Framework are externally reviewed as soon as possible and adjusted if necessary to accurately map the existing levels of service provision and inform quality improvement and planning of service development and expansion.

18.2.3 State-wide assessment of palliative care needs

The lack of an intentionally developed model of funding for palliative care, and the absence of a state-wide palliative care strategic plan means that palliative care resources are unlikely to be appropriately distributed. One submission noted that it is difficult to have priorities and distributions reconsidered given the current performance emphasis on acute hospital and emergency services.⁶³⁴

Several submissions argued that an adequate palliative care needs assessment for Queensland is required to underpin planning and resourcing, including planning for which specialist palliative care services provide consultation services and community palliative care, and in which locations. Palliative Care Queensland suggested that a Queensland needs assessment should take account of geographic and standard demographic information, and also vulnerable populations such as people with dementia, people of lower socio-economic status, Aboriginal and Torres Strait Islander peoples, and people from other cultural backgrounds.⁶³⁵ Palliative Care Australia said the principle for funding should be equitable support for all. Professor Vora argued that a more equitable system would result from funding based on geographical and population characteristics specifically related to palliative care.⁶³⁶ Palliative Care Queensland suggested that the Centre for Palliative Care Research and Education (a consortium of Queensland University of Technology, palliative care providers and General Practice Queensland) is ideally placed to prepare a Queensland population based palliative care needs assessment.⁶³⁷

The committee is persuaded by the view that needs-based planning of services is necessary, and considers that an assessment of population needs for palliative care, and planning for expansion of specialist palliative care services should be undertaken promptly.

In addition to needs-based population planning, a state-wide strategic plan should include a staged approach to expansion of specialist services according to priority population needs and practical constraints, including the recruitment of suitably qualified clinicians. As system manager, Queensland Health has a critical role in planning for the staged development of additional specialist palliative care services health services.

Recommendation 35 – Population-based palliative care needs assessment

The committee recommends that the Minister for Health ensure that a rigorous Queensland population-based palliative care needs assessment is completed as soon as possible, taking account of geography, demographics and factors relevant to the provision of palliative care, to provide a basis for service planning and future funding.

⁶³⁴ Professor Rohan Vora, Submission no. 73, p.2

⁶³⁵ PCQ, Submission no. 74, p.36

⁶³⁶ Professor Rohan Vora, *ibid.*, p.8

⁶³⁷ PCQ, *ibid.*, p.36

18.2.4 Resourcing and planning benchmarks

Queensland Health advised the committee that the currently endorsed planning benchmark for palliative care is 4.9 beds per 100,000 population. The benchmark is focussed on a 'designated' bed which supports palliative care provided by or with the support of a specialist in palliative care. The benchmark has historically been used for capital infrastructure planning, but benchmarks "do not determine if a service is to be delivered or established."⁶³⁸ Queensland Health advised the committee that a review of the planning benchmark for palliative care in Queensland was underway.⁶³⁹

The Queensland Health benchmark is lower than Palliative Care Australia's 2003 benchmark of a minimum of 6.7 palliative care beds per 100,000 population. The PCA service provision guide notes that this minimum benchmark needs to be supplemented in recognition of factors such as geographical location, higher proportions of people with complex needs or people who may not have carers available to support delivery of home-based care.⁶⁴⁰

Queensland benchmarks for provision of palliative care services and funding will need to take into account population, age demographics and disease projections as well as accounting for specific needs of individual specialist palliative care services such as the level of consultation-liaison service to other HHSs and primary care providers, travel costs and other factors that affect demands on service and budget differentially. Benchmarks will also need to ensure that the resourcing for specialist palliative care is adequate to cover the provision of services that may not be directly related to palliative care 'beds', such as consultancy-liaison services, bereavement counselling, home care equipment and support and co-ordination of volunteers.

Queensland Health will also need to develop robust, evidence based costing of quality specialist palliative care services to underpin planning and funding services in addition to, or as part of, a planning and resourcing benchmark. Such costing will need to adequately recognise the multidisciplinary and multi-setting nature of palliative care provision. Appropriate funding for co-ordination of community care, and co-ordination between hospital and contracted NGOs will need to be included as well as the range of functions to be expected of a specialist palliative care service, as outlined in Chapter 13.

Recommendation 36 – Planning and funding benchmarks

The committee recommends that the Minister for Health ensure that Queensland Health implement a review of planning benchmarks by population as soon as possible as a basis for decisions about the expansion, establishment and funding of additional palliative care services. The review should include consideration of resourcing levels for the range of functions required of specialist palliative care services.

18.2.5 Clear and transparent funding arrangements

Submissions to the committee noted a lack of clarity and transparency about the funding allocations for palliative care services. Palliative Care Queensland (PCQ) provided information on the funding available for palliative care in its submission and oral evidence. It noted that the total amount of funding provided to specialist palliative care services was not known, and listed those amounts that were known to it.⁶⁴¹ As noted above, the Minister for Health and Queensland Health provided information on the funding allocated for admitted public hospital subacute palliative care in 2010-11.

⁶³⁸ Queensland Health, Submission no. 35, p.9

⁶³⁹ Queensland Health, *ibid.*, p.9

⁶⁴⁰ PCA, *Palliative Care Service Provision in Australia: A Planning Guide*, p.18

⁶⁴¹ PCQ, Submission no. 74, p.23

Advice was also provided to the committee on the approximate Commonwealth and State funding provided for non-hospital based palliative care services in 2011-12.⁶⁴²

The committee believes that information on the provision and funding of palliative care in Queensland should be available to researchers, specialist palliative care services and stakeholder organisations to inform research and evaluation and support quality contributions to policy development.

Recommendation 37 – Reporting on funding

The committee recommends 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.

A number of submissions highlighted that including palliative care in the subacute care category in Commonwealth–State agreements was not helpful in ensuring an appropriate allocation to palliative care. The Senate inquiry into palliative care noted there is no published breakdown of palliative care funding in the subacute care funding category, affecting the level of transparency and accountability.⁶⁴³ It recommended the creation of a new activity based funding (ABF) category solely for palliative care, and the establishment of a palliative care advisory committee by the Independent Hospital Pricing Authority.⁶⁴⁴ Appropriate costing of palliative care and funding allocations should include the cost of providing care in the community sector.⁶⁴⁵

The Australian Healthcare and Hospital Association noted positively that the ABF structure would fund non-admitted health services provided anywhere.⁶⁴⁶ At the same time, some submissions indicated that, while ABF might provide some improved flexibility for palliative care, it would be important to ensure that the ABF did not limit important aspects of palliative care such as consultation liaison services in acute hospitals, services to carers and family, and services delivered by a multidisciplinary team.^{647,648}

Recommendation 38 – Separate palliative care from ‘subacute’ funding

The committee recommends 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 funding should be separated from ‘subacute’ funding.

⁶⁴² Queensland Health, *ibid.*, p.5

⁶⁴³ Senate Committee inquiry, *Palliative care in Australia*, p.44

⁶⁴⁴ Senate Committee inquiry, *ibid.*, Recommendation 2, p.45

⁶⁴⁵ Senate Committee inquiry, *ibid.*, Recommendation 2, pp.45–6

⁶⁴⁶ Australian Health and Hospitals Association, Submission no. 22, p.4

⁶⁴⁷ PCA, Submission no. 69, p.8

⁶⁴⁸ PCA, *ibid.*, p.8

Recommendation 39 – National funding

The committee recommends that the Minister for Health write to the Commonwealth Minister for Health to:

- support the Senate committee’s Recommendation No. 3 that the Independent Hospital Pricing Authority (IHPA) establish a palliative care advisory committee to advise on appropriate costing of palliative care services
- propose that the IHPA 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.

18.3 Providing additional palliative care services

Health reform creates opportunities for new and more planned approaches to the funding and provision of palliative care. There are opportunities to reform palliative care models of funding so that emerging needs are better met, particularly with regard to approaches to funding that recognise the need for diversity in provision.⁶⁴⁹

In Chapter 13, the committee explored the role of specialist palliative care services, particularly to ensure that higher level specialist services can support GPs and other health providers in a palliative approach to care.

Ensuring that specialist palliative care services are properly resourced for a full range of functions will mean that they can more effectively support primary health care providers. Quality specialist palliative care services (generally those at Level 4, 5 and 6) will need to be funded to provide 24-hour access for patients and primary care providers, training, consultancy-liaison services, bereavement services, palliative care equipment and volunteer co-ordination.

A comprehensive state-wide plan for palliative care in Queensland, the assessment of needs and the review of planning and resourcing benchmarks addressed earlier in this section will mean that funding can be provided more equitably according to population and needs across Queensland’s regions.

The committee considers that the funding available to existing specialist palliative care services (particularly Level 4, 5 and 6 in the Clinical Services Capability Framework), and the potential for funding of additional specialist palliative care services in other regional areas, based on a population needs assessment, should be investigated as soon as possible. The committee believes that progressive expansion of the capacity of specialist palliative care services to support a palliative approach in the community will see improvements in palliative care in Queensland.

It is unlikely that in the short term there will be sufficient palliative care physicians, nurse practitioners, specialist nurses, allied health professionals and bereavement counsellors available to staff specialist palliative care services in all regional areas. It will also be necessary to progressively allocate resources to ensure that existing and additional specialist palliative care services are adequately resourced to fulfil consultancy, after-hours on-call community care and other roles required.

The committee is persuaded that the government should commit to providing additional funding for palliative care and establishing more specialist palliative care services using a staged approach and in line with consideration of the planning and benchmarking work recommended above.

⁶⁴⁹ Australian Health and Hospitals Association, Submission no. 22, p.4

In addition to the expanded funding that will be required to resource the range of activities required of specialist palliative care services and establish services where needed, the committee notes that other recommendations in this report have direct funding implications. Those recommendations include:

- provision of a 24-hour telephone information service (Recommendation 1)
- funding for a children’s hospice (Recommendation 3)
- provision of resources for medication systems (Recommendation 12)
- funding for more hospices and hospice beds (Recommendation 16)
- scholarships to qualify as nurse practitioner (Recommendation 19)
- funding of demonstration and pilot projects in assistive technology (Recommendation 46)
- funding of a respite program (Recommendation 53)
- provision of counselling services for carers (Recommendation 57)
- provision of carer training (Recommendation 58)

18.4 Queensland Health – system manager role

Within a broad state-wide strategy it is expected that Queensland Health will have an active role as system manager in planning and influencing the shape of palliative care services delivered by Hospital and Health Services and other health and care providers. The establishment in 2012 of Hospital and Health Services and a changed role for Queensland Health as system manager creates the opportunity to take a whole of system approach to palliative care planning, with the additional benefits of local needs assessment by HHSs. Queensland Health’s role was described by the Minister for Health:

*... as a system manager, is a mechanism which will ensure oversight of clinical standards. We have governance, we have regulation requirements—all of those sorts of things—and there will be certain things that have to be ensured. We ensure there is a central coordination role. That is already envisaged.*⁶⁵⁰

*... there are not the number of specialist palliative care services throughout the state and there will be a requirement to take some leadership in relation to providing specialist palliative care services in particular geographic locations by virtue of the availability of workforce and the capacity of the particular hospital and health service to actually do that. So that is part of the role of the system manager and it is part of the role in terms of planning for state-wide services into the future and strategies in relation to provision of palliative care.*⁶⁵¹

The committee believes that Queensland Health should utilise service agreements, directives and standards⁶⁵² to ensure that, to the greatest extent possible, there is equitable access to palliative care across the state. It is not possible to provide highly specialised services in all locations, but good planning and co-ordination can ensure that quality care is accessible according to need. Importantly, the system funding arrangements managed by Queensland Health should not impede the delivery of person-centred palliative care wherever it is needed.

Queensland Health has a number of critical roles in planning. In its role as system manager, Queensland Health should provide incentives for HHSs to develop plans for the delivery of palliative care that is consistent with the state-wide strategy, and that reflects evidence of local needs. Incentives and directives should encourage the delivery of care that emphasises person-centred care

⁶⁵⁰ Hon. Lawrence Springborg MP, *Public Hearing Transcript*, 22 August 2012, p.25

⁶⁵¹ Graham Kraak, Director, Older People’s Health and Extended Care Unit and Cancer Control Team, Queensland Health, *Public Hearing Transcript*, 22 August 2012, p.26

⁶⁵² Service agreements, directives and standards are referred to in the *Health and Hospitals Network Act 2011*, Section 45, Functions of chief executive, available at <http://www.legislation.qld.gov.au/LEGISLTN/ACTS/2011/11AC032.pdf>

that meets individual needs. Specialist palliative care services should be provided with incentives to put increased emphasis to provision of palliative care services in people's homes and residential aged care facilities, consultation services to other health professionals, and to support and develop the capacity of less specialised and generalist services to provide quality palliative care.

Measures should be introduced to ensure that all HHS services operate within the framework of the Clinical Services Capability Framework, for example by having clear arrangements to access appropriate specialist palliative care consultancy advice from another health service when needed.

Recommendation 40 – Specialist palliative care service resourcing and delivery

The committee recommends that the Minister for Health ensure that Queensland Health plans for and supports implementation of accessible specialist palliative care across Queensland and that, in its system manager role, uses service agreements and purchasing arrangements to ensure that Hospital and Health Services:

- deliver more palliative care services in the home and community
- implement the Clinical Services Capability Framework
- make constructive links between specialist palliative care services and general health services to ensure that specialist palliative care consultation services are readily accessible to all Hospital and Health Service facilities
- implement case management
- ensure discharge planning is carried out, and
- deliver specialist palliative care services that:
 - o develop greater capacity to deliver care in the home and in residential aged care facilities, so that patient preferences are met and the costs associated with unwanted and unnecessary admission are reduced
 - o provide 24-hour telephone and home visiting support to existing clients
 - o provide specialist consultancy and liaison services to other public sector facilities and to general practitioners
 - o adopt models of care that use specialist nurse practitioners
 - o provide training for palliative care specialists to build capacity to meet increasing needs for palliative care
 - o provide bereavement counselling and
 - o support the provision of equipment and training for care in the home.

18.5 Innovation and knowledge

Hospital and Health Services should be encouraged and supported to adopt approaches to service delivery that have proven to be effective. To this end, Queensland Health should ensure that innovative models of care are evaluated, and that there are effective mechanisms for exchange of knowledge and expertise between clinicians and care providers across Queensland.

The committee is of the view that research and evidence based approaches to interventions and models of care will need to be undertaken and that this should be commissioned and funded if necessary.

Recommendation 41 – Evaluation and best practice

The committee recommends that the Minister for Health ensure that:

- innovative models of palliative care in Queensland are evaluated, so that success factors can be identified to contribute to practice and quality improvement
- Queensland Health provide information and guidance to Hospital and Health Services about best practice delivery of person-centred palliative care, and
- a program of research is established and resourced to evaluate models of palliative care provision, standards and outcomes.

Part 4 Community care and home care services in Queensland – future directions

Chapter 19. Capacity, adequacy and effectiveness of community care services

19.1 Introduction

The committee's terms of reference require it to consider the capacity, adequacy, effectiveness and efficiency of Queensland's Community Care services. Chapter 5 of the report provides a starting point for the committee's consideration of the matter by briefly describing current service provision for both community care services and home and community based specialist disability care.

The committee received very limited evidence about Community Care services, which may reflect confusion about the separation of the former joint HACC program into separate age-based Commonwealth and State responsibilities in July 2012. While some submissions and witnesses commented on 'HACC services' it was not always clear whether comments were about HACC services for older people (an Australian Government responsibility since July 2012), pre-2012 HACC services for all age groups, or post-July 2012 Queensland Community Care Services for people under 65 (or under 50 if Aboriginal or Torres Strait Islander). In this chapter the committee has drawn on the evidence which appears to be about services for people aged under 65 (or under 50), which are the responsibility of the Queensland Government.

Evidence about HACC services is discussed in the context of the separation of Australian and Queensland Government responsibilities, in Chapter 24, as required by the committee's terms of reference.

19.2 Information, eligibility and access to Queensland community care services

To obtain Queensland Community Care Services, potential clients need information about what services are available and who is eligible, the application and assessment requirements, and reasonable access to services. Increasingly, consumers of services seek access to services in ways and at times that are flexible.

19.2.1 Adequacy of information

A number of submitters were concerned about the adequacy of information about Queensland Community Care Services. A Brisbane carers group said carers have little or no knowledge of many elements of service provision, including what services are available, how they can be accessed, who provides services and the eligibility requirements.⁶⁵³ Carers Queensland raised similar issues and stated carers have "... repeatedly voiced concerns about unmet needs for information on appropriate services".⁶⁵⁴

Carers also stated that they find it difficult to communicate with government departments and service providers, as they "... are not always confident with modern technology...", find acronyms confusing and believe that many front line service staff are "ageist" or do not know what services their organisation provides.⁶⁵⁵

Youngcare, which advocates that young Australians with high care needs should be able to receive care at home rather than in residential aged care, also argued that people should have access to relevant information and advice to enable them to make decisions and choices relevant to their

⁶⁵³ The Carers' Group Bulimba, Submission no. 34, p.1

⁶⁵⁴ Carers Queensland, Submission no. 9, pp.7–10

⁶⁵⁵ The Carers' Group Bulimba, *ibid.*

needs. Youngcare currently meet this need by operating Youngcare Connect, a support and advice hotline which connects younger adults with high care needs to relevant information about government and health care services.⁶⁵⁶

19.2.2 Information about access

A Queensland Government web page, *Access to Community Care Services*, states that people who wish to receive community care should phone their local 'Community Access Point' on a toll free phone number.⁶⁵⁷ It is difficult to find further information about Community Access Points such as operating hours or information about local services.

The committee was informed in August 2012 that Blue Care and Ozcare were participating in a trial of Community Access Points under the auspices of the Department of Communities, Child Safety and Disability Services (Department of CCSDS). The trial sought to establish a consistent pathway for people to access Queensland Community Care Services through "... a phone number that people can ring that will have a database with all of the services and the service availability on it"; in essence, a one-stop shop.⁶⁵⁸ The committee understands this trial is to be completed in June 2013.

The committee explored options for a 'one-stop-shop' with several witnesses. Glenys Webby described her concept of a 'one-stop shop' as a central point of intake which provides information, assesses eligibility, makes referrals to service providers and coordinates and case manages if clients need services from multiple providers. Ms Webby argued that 'one-stop shops' would operate best at a regional level, where staff have local knowledge about service availability and provision.⁶⁵⁹

Ms Webby described future challenges for Community Access Points as:

*... about how we get people through them quickly to the services that they need whilst not requiring them to continue to go back to be reassessed.*⁶⁶⁰

The committee considers that currently available information about access to Queensland Community Care is inadequate and that this may delay clients' access to services. The trial of Community Access Points is intended to provide a central and consistent access pathway and the committee considers that the trial should be evaluated to provide information about effectiveness that can inform future service models.

The committee considers that a model like Community Access Points may address concerns about adequacy of information and timely access to services. The committee sees the benefit of a seamless link between a single phone number and a regional information, assessment and referral service which has the benefit of local knowledge, for example, about which services have waiting lists. If regional services have this role, they could also provide case management when needed, which may not be as feasible for a state-wide service.

⁶⁵⁶ Youngcare, *Youngcare Connect*, accessed 17 April 2013 from <http://www.youngcare.com.au/page.aspx?pid=480>

⁶⁵⁷ Queensland Government, *Access to Community Services*, accessed 17 April 2013 from <http://www.qld.gov.au/community/getting-support-health-social-issue/access-community-care-services/>

⁶⁵⁸ Glenys Webby, *Public Hearing Transcript*, 24 August 2012, p.24

⁶⁵⁹ Webby, *ibid.*, p.26

⁶⁶⁰ Webby, *ibid.*, pp.24 & 26

Recommendation 42 – Queensland Community Care – information, referral, assessment

The committee recommends that the Minister for Communities, Child Safety and Disability Services, in consultation with the Minister for Science, Information Technology, Innovation and the Arts, ensure that a seamless information, assessment and referral service is implemented to assist potential Community Care clients to access services. The committee recommends that the Minister ensures that the model:

- builds on the outcomes of the Community Access Point trial
- links consumers to a person with current regional or local knowledge of relevant services
- provides information about Community Care and other relevant services
- undertakes eligibility screening, initial assessment, referral and co-ordination
- employs effective referral and assessment, which minimises the impost on clients and does not require multiple assessments
- promotes consumer choice and responsive service provision
- provides case management for clients who receive services from multiple providers, and
- is supported by up-to-date web-based information.

19.2.3 Information about eligibility

While information about eligibility for Queensland Community Care is reasonably easy to find on the internet, the level of concern identified in submissions suggests that eligibility requirements for Queensland Community Care are not easily understood or applied to potential consumers. Some level of screening or assessment would be required to establish certain elements of the eligibility criteria. For example, whether the person has a “moderate, severe or profound disability, or a condition which restricts the ability to carry out activities of daily living”⁶⁶¹ would need to be assessed. The committee believes that the implementation of seamless eligibility and assessment services, as recommended above, will increase understanding of the eligibility criteria and how to apply them.

19.2.4 Assessment of eligibility and care need

A number of submissions outlined difficulties with the current Queensland Community Care assessment process. Carers Queensland stated their members experience “excessive delays” in obtaining a community care assessment and “even longer delays” securing culturally appropriate care.⁶⁶² Another carers group saw application forms that duplicate information requests as a barrier to timely service provision and described the interviews which form part of this process as time consuming and draining, particularly when much of this information is “... already available from some other agency or government section”.⁶⁶³

Carers of younger children with a disability described similar experiences; one mother completed a 60 to 80 page application for Disability Services Queensland (part of the Department of CCSDS).⁶⁶⁴

The intent of assessment for Queensland Community Care Services is to “minimise(s) the impost on clients.” Service providers are encouraged to cooperate and coordinate at the local level to minimise duplication of assessments by using common tools, processes and referral systems which prevent clients having to provide the same information to multiple organisations and service providers.⁶⁶⁵

⁶⁶¹ Queensland Government, *Access to Community Services*

⁶⁶² Carers Queensland, Submission no. 9, p.7

⁶⁶³ The Carers’ Group Bulimba, Submission no. 34

⁶⁶⁴ Name suppressed, Submission no. 33

⁶⁶⁵ DCCSDS, *Manual for Queensland Community Care Services*, p. 9

Assessment could see a Queensland Community Care client involved in up to four separate assessments:

- an initial assessment to determine eligibility, completed by either a service provider or a Community Access Point
- a service level assessment to develop a care plan, completed by the service provider
- a comprehensive assessment – if complex care needs are evident – completed by a service provider. As not all providers are funded for this assessment type, unfunded providers must refer clients to another service provider. The information currently available on the Department's website about Community Access Points does include information on organisations funded to complete comprehensive assessments, and
- a specialist assessment if clients require a level of service beyond what can be provided through Queensland Community Care. Service providers refer the client to the relevant programs or services for assessment.⁶⁶⁶

The committee encourages the Minister to ensure that the Queensland Community Care program minimises the impact of multiple assessments on clients and consider ways it can reduce duplication of assessments.

19.2.5 Assessment of carers' needs

Carers Queensland states carers do not feel adequately supported or recognised in their role⁶⁶⁷ and advocates for the development of a carer specific assessment and early intervention services. This issue was common among carers groups and is discussed in detail in Chapter 22.

19.3 Service capacity and future needs

The committee received limited evidence about the capacity of Queensland Community Care Services to meet current needs. A small number of submitters raised qualitative issues about flexible and consumer driven services, which indicated that services are not necessarily being provided in the way that consumers want. This could suggest that the capacity of services is stretched, or that consumer expectations about how and when services are delivered have changed. This matter is discussed in more detail in Chapter 20.

19.3.1 Levels of service provision and use

The Department of CCSDS advised that at 30 November 2012 it funded approximately 230 Queensland Community Care organisations, and services were delivered by about 618 service providers.⁶⁶⁸

Most Queensland Community Care clients receive a low level of services. In June 2012 clients received the following:

- **Low use group** – 52 per cent received less than one hour of service per month, most commonly nursing care, allied health and home maintenance. Ten per cent of this group also received specialist disability services⁶⁶⁹
- **Medium use group** – 44 per cent received between one hour per month and up to a few hours per week of service. Twenty-six per cent of this group also received specialist disability services.
- **High use group** – 4 per cent received more than one hour of service per day. Fifty-five per cent of this group of clients also received specialist disability services.

⁶⁶⁶ DCCSDS, *ibid.*, pp.10–11

⁶⁶⁷ Carers Queensland, *ibid.*, pp 7–10

⁶⁶⁸ DCCSDS, Submission no. 76, p.8

⁶⁶⁹ DCCSDS, *ibid.*, pp.8–9

The Department of CCSDS advised that up to one-third of clients exit the system each year, one-third of clients enter each year, and the remaining third continue.⁶⁷⁰ In 2010-11, sixty-seven per cent of clients under 65 (under 50 if Aboriginal or Torres Strait Islander) had a disability, seven per cent had a mental health condition and twenty five per cent had a chronic health disease.⁶⁷¹

The Department of CCSDS noted that the high percentage of clients with a chronic condition highlights the importance of collaboration across service systems and shared responses to better meet client need. The Department of CCSDS also acknowledged that one of the key areas requiring attention in the future is greater clarity about the responsibility between community care and palliative care services. These issues are discussed in *Part 6*.

19.4 Workforce capacity

19.4.1 Health and community services workforce

The health and community services industry is Queensland's largest employer, with 282,854 people or 12.2 per cent of the state's total labour market in February 2012.⁶⁷² It is one of the fastest growing industries, and has grown 57 per cent over the past decade. This rapid growth is predicted to continue; a quarter of the new jobs created in Australia in 2015–16 are projected to be in the industry.⁶⁷³ Mr Westbrook, of the Health and Community Services Workforce Council, advised the committee that the industry has outstripped mining by about two-to-one or three-to-one each year for the last five years and is responsible for approximately 43 per cent of all employment growth in Queensland over the last five years.⁶⁷⁴

19.4.2 Community services workforce profile

The community services sector is one of the largest sectors (41 per cent) of the health and community services industry, employing approximately 114,100 people or 4.9 per cent of Queensland's total labour market at May 2011.⁶⁷⁵

The workforce profile in 2012 was older than average; the average age was 43, compared to 39 for all other industries. Only ten per cent of the workforce was under 25 years, compared to 16.9 per cent for all industries and a significant proportion of the workforce was expected to reach retirement age within five to ten years.⁶⁷⁶ This aggregate data includes employees in a number of areas other than Queensland Community Care Services. The committee believes the workforce profile is likely to reflect the Queensland Community Care workforce, as many employees to work across the industry.

An estimated 66,000 volunteers were working in community services in June 2009. The Workforce Council described this level of community engagement as "... extremely positive for the industry, but does present some unique workforce challenges".⁶⁷⁷ The challenges include increased competition

⁶⁷⁰ DCCSDS, *ibid.*, p.9

⁶⁷¹ DCCSDS, *ibid.*, p.9

⁶⁷² ABS, 6291.0.55.003 *Labour Force, Australia, Detailed, Quarterly, February 2012*, available at <http://www.abs.gov.au/Ausstats/abs@.nsf/0/1701C1F8FDA9BF77CA257A1C00117E6A>

⁶⁷³ Health and Community Services Workforce Council, *Industry Overview-Industry Skills and Workforce Development Report for the Health and Community Services Industry*, June 2012, pp.9-10, available at <http://www.workforce.org.au/media/243136/wfc-industry-skills-report-web.pdf>

⁶⁷⁴ Wallis Westbrook, Health and Community Services Workforce Council, *Public Roundtable Discussion Transcript*, 28 November 2012, p.6

⁶⁷⁵ Health and Community Services Workforce Council, *Community Services Sector – Industry Skills and Workforce Development Report*, June 2012, p.4, available at <http://www.workforce.org.au/media/242664/wfc-industry-skills-report-community-services-sector-2012-09-24.pdf>

⁶⁷⁶ Health and Community Services Workforce Council, *ibid.*, p.11

⁶⁷⁷ Health and Community Services Workforce Council, *ibid.*, p.4

for volunteers, due to relatively low rates of unemployment and decreasing rates of voluntarism, and limits on the level of resources available to sustain some volunteer programs.⁶⁷⁸

19.4.3 Workforce challenges and barriers

A number of population and health trends present challenges to the capacity of the community services workforce to meet future needs. The key trends include the projected growth of the Queensland population, which is increasing more rapidly than the Australia average, and the impact an ageing population will have on need for services, because of increased longevity, disability and disease and extended life expectancy.⁶⁷⁹

Economic, social and environmental factors are also likely to impact on the ability of the community care sector to meet future needs. These factors highlight the need for the sector to:

- cater for an increasingly diverse population, with an expected increase in the number of clients from non-English speaking backgrounds
- respond to recent government reforms in the health and community sectors
- undertake workforce planning to ensure future needs can be met
- develop an improved understanding of how to prepare for and respond to natural disasters, and
- move towards more integrated service delivery and a corresponding need for “... high-level skills in workforce management, workforce planning, change management and innovation...” as services strive to meet changing policy and client expectations.⁶⁸⁰

Barriers to recruiting and retaining an adequately skilled workforce include low wages, limited resources to invest in training and workforce development, high levels of ‘worker stress’ as a result of increased service demand and labour shortages, and limited capacity among small, not for profit services to undertake strategic workforce planning.⁶⁸¹ Wallis Westbrook expanded on this theme and described the most significant barriers to workforce capacity as:

- poor remuneration, which contributes to a perception that the work is not valuable
- a perceived lack of career pathways, which means young people are unlikely to identify the sector as one in which they might have a career
- extensive time spent on accountability and compliance activities by people who want to provide direct, hands-on-care.⁶⁸²

Mr Westbrook suggested a promotional campaign to highlight the value of community services should be considered. Advertising campaigns in mining and in the Western Australian disability sector have succeeded in changing the views of the community about what happens in these sectors.⁶⁸³

The committee considers that an adequately skilled workforce is pivotal to client focused community care, and demographic, social and economic pressures present a challenge. Significant work is needed in workforce promotion and planning to ensure that there is adequate workforce capacity to meet future needs for community care. The committee considers that more information is needed to plan for sufficient workforce capacity, and recommends that research is commissioned to underpin this.

⁶⁷⁸ Health and Community Services Workforce Council, *ibid.*, p.10

⁶⁷⁹ Health and Community Services Workforce Council, *ibid.*, pp.4 & 7

⁶⁸⁰ Health and Community Services Workforce Council, *ibid.*, pp.7–9

⁶⁸¹ Health and Community Services Workforce Council, *ibid.*, pp.4 & 10

⁶⁸² Wallis Westbrook, *ibid.*, p.4

⁶⁸³ Wallis Westbrook, *ibid.*, p.8

Recommendation 43 – Community care workforce

The committee recommends that the Government consider implementing a promotional campaign aimed at changing public perceptions of community care and its workforce. A campaign should aim to promote and highlight:

- the social value of caring for people
- the size of the community care sector and its contribution to Queensland’s economy, and
- the range of jobs and career pathways available in community care.

Recommendation 44 – Research and planning for community care workforce capacity

The committee recommends that the Government commission research on the community care workforce in Queensland to:

- provide an assessment of future community care workforce needs to meet expected increases in need for services, taking account of the ageing workforce and population, and
- develop strategies to ensure that the community care workforce has capacity to meet future needs, including active workforce planning, recruitment, training pathways and workforce retention.

19.5 Future needs for community care services

19.5.1 Potential increased levels of need

The committee received limited evidence about the future need for Queensland Community Care Services. The Workforce Council predicts the community services sector will grow rapidly over the next ten years, as the Queensland population continues to increase more rapidly than the Australian average.⁶⁸⁴ The committee considers the combination of population and workforce trends and economic, social, and environmental factors is likely to result in increased future need for community care services.

19.5.2 Role of technology in addressing increasing levels of need

The committee heard evidence that new and emerging technologies, including assistive technology, have the potential to assist in meeting future needs for community care services. The use of technology is discussed in the next chapter.

⁶⁸⁴ Health and Community Services Workforce Council, *Community Services Sector – Industry Skills and Workforce Development Report.*, p.4 & p.13

Chapter 20. Improving service adequacy, effectiveness and efficiency – needs-based and person-centred services

20.1 Introduction

The committee's terms of reference require it to consider the capacity, adequacy, effectiveness and efficiency of Queensland's Community Care services and to examine opportunities for reform to ensure future service provision needs are met.

The committee's comments are constrained by limited evidence. In addition, it was unclear whether submissions about person-centred care commented on HACC services for older people, pre-2012 HACC services for all age groups or post-July 2012 Queensland Community Care Services for people under 65. The committee has drawn on the evidence which appears to be about services for people aged under 65, now the responsibility of the Queensland Government.

20.2 Flexible, person-centred services

Flexible and consumer driven services are becoming increasingly important to community care recipients. A number of submissions advocate for more flexible models of service delivery, rather than a one-size fits all approach, and argue that the sector should be opened up, to both new and private providers, to drive improvement and widen choice.⁶⁸⁵

20.2.1 Inflexible service provision and changing expectations

One current home care worker described community care services as "woeful", restricted in frequency and duration and focused primarily on cleaning and domestic duties.⁶⁸⁶ Carers Queensland also said that service provision was inflexible and unresponsive.⁶⁸⁷ Youngcare claimed that younger adults with high care needs have a very limited choice of care and accommodation. Youngcare supports the development of "relevant and appropriate care models" to support younger adults with high care needs to "live young, dignified and relevant lives".⁶⁸⁸

20.2.2 Service providers and person-centred care

Several service providers recognised the importance of flexible person-centred care, and informed the committee about their models of care. Potential consumers of care services want to be able to choose from a variety of services which suit their needs, and to decide when and where those services are delivered. They want to be able to direct and personalise services, to meet changing circumstances, preferences and needs, and be assured that service providers will be flexible and responsive.⁶⁸⁹

Home Instead, a private provider of home-based services, argued that its success in recent years "... clearly demonstrates a growing demand for *quality* and *reputable* in-home care, *responsive* to client's needs to support them to live independently and retain their quality of life."⁶⁹⁰ Home Instead described its services as 'client-centred and client-directed.' Clients are able to choose the type, frequency and length of services to meet their daily needs. Services are available 24-hours a day, seven days a week and may be changed by clients as their needs change.⁶⁹¹

⁶⁸⁵ Home Instead Senior Care, Submission no. 7; and Care Connect, Submission no. 23

⁶⁸⁶ Lorna McConnachie, Submission no. 2

⁶⁸⁷ Carers Queensland, Submission no. 9, pp.7–10

⁶⁸⁸ Youngcare, Submission no. 10

⁶⁸⁹ Home Instead Senior Care, Submission no. 7 and CareConnect, *Our approach*, accessed 14 April 2013 from <http://www.careconnect.org.au/About-us/Service-delivery>

⁶⁹⁰ Home Instead Senior Care, *ibid.*

⁶⁹¹ Home Instead Senior Care, *ibid.*

Care Connect, a not for profit case management and care services provider, has a model of person-centred care called titled 'My Life, My Choice, My Way', which recognises that clients wish to have control of their lives and be at the centre of decision making.⁶⁹²

Blue Care's Tailor Made model is based on a similar premise, which aims to design and deliver services that are tailor-made to the individual and delivered in a way that clients are able to control.⁶⁹³

The committee notes that the *Manual for Queensland Community Care Services* provides guiding principles for service providers, which include optimising client choice, providing tailored services and ensuring responsive service provision.⁶⁹⁴ The committee considers it likely that further work is needed to implement person-centred care.

20.2.3 Funding arrangements

Both Home Instead and Care Connect suggested that the community care sector should be opened up to both new and private providers. Home Instead delivers brokered services on behalf of funded Queensland Community Care service providers, and stated that many funded service providers "... are struggling to meet the level of consumer directed care that clients and their families now demand – in fact they rely on us to fill the gap of their less flexible and agile services."⁶⁹⁵ It argued that greater private service provision could address unmet need, provide greater consumer choice, increase competition, and drive improvements in service quality and value.⁶⁹⁶ Care Connect argued that current funding arrangements prevent Queenslanders from "... accessing services from some of Australia's largest and most innovative organisations" and states opening up the system to new providers would increase competition and innovation.⁶⁹⁷

The committee notes that the Department of CCSDS website states that organisations may express interest in providing Queensland Government-funded Community Care services by email.⁶⁹⁸

20.3 Equipment and technology

A number of submissions describe the difficulties associated with sourcing, obtaining and affording the equipment required to care for a person at home. Those difficulties were most commonly raised by carers of young children with a life limiting condition who received some services from Queensland Community Care, as well as palliative care. Equipment for palliative care at home is discussed in section 12.8.

20.3.1 Equipment

Several submitters described complex and time consuming efforts to obtain the equipment required, particularly for a child with complex care needs. Their experience also highlighted the lack of clarity about accessing equipment from either or both Queensland Community Care Services and the Medical Aids Subsidy Scheme (MASS).

For example, Fiona Engwirda described securing equipment for her disabled daughter who had a life-limiting condition, as complex and reliant on her ability to advocate within the system.⁶⁹⁹ Mrs Engwirda gave a detailed description of the equipment and the multiple places from which it was

⁶⁹² CareConnect, *Our approach*,

⁶⁹³ Glenys Webby, *Public Hearing Transcript*, 24 August 2012, p.22

⁶⁹⁴ DCCSDS, *Manual for Queensland Community Care Services*, p.5

⁶⁹⁵ Home Instead Senior Care, Submission no. 7

⁶⁹⁶ Home Instead Senior Care, *ibid.*

⁶⁹⁷ CareConnect, Submission no. 23

⁶⁹⁸ DCCSDS, *Community Care funding*, accessed 24 April 2013 from <http://www.qld.gov.au/community/community-organisations-volunteering/community-care-funding/>

⁶⁹⁹ Fiona Engwirda, Submission no. 70, p.99

sourced, to illustrate the complexity of the exercise. The family paid for some equipment themselves, or made a significant contribution to its cost.⁷⁰⁰

Queensland Health acknowledged that meeting the equipment and support needs of children with life limiting conditions can be very expensive and noted the importance of both disability services and the MASS being responsive and providing equipment and services in a timely manner.⁷⁰¹ Palliative Care Queensland supported this view.⁷⁰² The evidence from submissions suggests however that the existing equipment services are not experienced by consumers as responsive and timely.

20.3.2 Queensland Community Care and the Medical Aids Subsidy Scheme

Under Queensland Community Care, equipment includes "... the loan or purchase of goods and equipment to assist the person to cope with a disabling condition and/or maintain their independence." The *Manual for Queensland Community Care Services* states that the program does not generally purchase these items "because complementary programs exist such as the Medical Aids Subsidy Scheme (MASS)". The manual states that any items which are purchased remain the property of the organisation.⁷⁰³

The MASS provides "access to subsidy funding for the provision of MASS endorsed aids and equipment to eligible Queensland residents with permanent and stabilised conditions or disabilities."⁷⁰⁴ Aids and equipment are intended to assist people to live at home, to avoid premature or inappropriate residential care or hospitalisation, and can include communication aids, continence aids, daily living aids, medical grade footwear, mobility aids, orthoses, oxygen, spectacles and equipment associated with the treatment of cystic fibrosis.⁷⁰⁵

Palliative Care Queensland describes the process of accessing MASS funding as extremely complex, time consuming and resource intensive.⁷⁰⁶ The interface between MASS and Queensland Community Care Services is confusing. Application forms for MASS are complex and must be completed by a designated prescriber, who is generally a health professional, in consultation with the applicant.⁷⁰⁷ It is unclear whether an applicant for equipment from Queensland Community Care is the service provider or consumer.

The committee considers that information about eligibility for equipment and how to obtain it is inadequate, particularly in relation to the interface between Queensland Community Care Services and the MASS. The committee considers that the level of complexity and lack of clear information is a barrier to obtaining equipment. The committee believes it is important that there is clear information about eligibility for assistance with equipment, and timely access to those who are eligible.

⁷⁰⁰ Fiona Engwirda, *ibid.*, p.10

⁷⁰¹ Queensland Health, Submission no. 35, p.14

⁷⁰² PCQ, Submission no. 74, pp.46–7

⁷⁰³ DCCSDS, *ibid.* p.19

⁷⁰⁴ Queensland Health, *Medical Aids Subsidy Scheme Home Page*, accessed 17 April 2013 from <http://www.health.qld.gov.au/mass/>

⁷⁰⁵ Queensland Health, *ibid.*

⁷⁰⁶ PCQ, *ibid.*, p.31

⁷⁰⁷ Queensland Health, *ibid.*

Recommendation 45 – Equipment services

The committee recommends that the Minister for Health and the Minister for Communities, Child Safety and Disability Services collaborate to consider and implement the most effective service model to provide equipment, including:

- consideration of a single integrated equipment service
- clear public information about eligibility criteria and how to apply for assistance with equipment, and
- timely provision of equipment to support people at home.

20.3.3 Assistive technology and ambient living

The committee received evidence from LifeTec about the potential for assistive technology and ambient living to help meet future needs for community care. The committee visited the Brisbane LifeTec centre to gain an understanding of the available assistive technologies and ambient living.

Assistive technology is any product, device or system that provides people with practical solutions to everyday life activities and which assists them to live independently and improve their quality of life. Examples of assistive technology include devices that help in daily living independence, communication and mobility, monitoring of a person and their environment (e.g. movement detectors), electronic systems to control appliances, home modifications, prosthetics and orthotics, sensory aids (e.g. speech output devices), and devices to enable participation in recreation (e.g. audio description for movies).⁷⁰⁸

Ambient living is the incorporation of assisted technology into a person's environment and is commonly considered in settings which cater for people who are older or have a disability. LifeTec has centres in Brisbane and Townsville to demonstrate assistive technologies which can be used to create ambient living. James Barrientos of LifeTec emphasised the capacity of assistive technology to prevent inappropriate hospital admissions. He described a LifeTec project which connected allied health providers with local staff and clients using an iPad for a virtual assessment of home modification needs. Allied health professionals were not required to travel and could complete more assessments in a timely manner. The use of relatively common technology facilitated assessments for clients who had been waiting for a significant period of time for home modifications.⁷⁰⁹

Glenys Webby from Blue Care informed the committee of an assistive technology pilot it ran using a range of devices in people's homes, which was being evaluated, and that Blue Care has implemented a range of telecare devices in its programs in home care.⁷¹⁰ Blue Care provided the committee its report on a pilot of the use of sensor lights, personal alarms, automated medicine dispensers, falls detectors and a watch promoting regular nutrition. It found positive improvements in quality of life, high client satisfaction with sensor lights and personal alarm technologies, and variable responses to the watch. Lower uptake of other technologies meant that satisfaction or outcomes could not be determined.⁷¹¹

The committee considers there is great potential for assistive technology to be used widely and successfully in community care to meet the growing need for person-centred care services. While adoption rates for assistive technology have been low, there is potential for increased uptake, both with more promotion of the benefits, and the use of familiar technologies with which people are comfortable.

⁷⁰⁸ LifeTec, *Assistive Technology*, accessed 15 April 2013 from <http://www.lifetec.org.au/home/content.asp?pageid=198>

⁷⁰⁹ James Barrientos, *Public Hearing Transcript*, 24 August 2012, p.10

⁷¹⁰ Glenys Webby, *Public Hearing Transcript*, 24 August 2012, p.23

⁷¹¹ Blue Care, *Assistive Technology Demonstration Project*, November 2012, UnitingCare Queensland, Brisbane

In light of the potential for innovative uses of assistive technology in community care, and its slow uptake, the committee recommends that the Government provide additional resources for demonstration and pilot projects and research to contribute to positioning Queensland as a leader in the use of technologies in community care services. The committee considers that an increase in investment in the short term to build on existing academic and service provider expertise in assistive technology could yield significant future savings, and facilitate more consumer choice about care services.

An increase in funding for demonstration and pilot projects could develop effective models of care; promote the uptake of cost-effective technologies; and increase awareness and knowledge of the benefits of assistive technology. There may be benefit in providing funding to partnerships or consortia that can bring together the knowledge and expertise of academics, non-government and private sector service provider organisations and advocacy organisations to promote innovation and knowledge transfer.

Recommendation 46 – Assistive technology demonstration and pilot projects

The committee recommends that the Minister for Communities, Child Safety and Disability Services consider providing resources for demonstration and pilot projects and research in the use of assistive technology in community care. Those projects should have the potential to:

- develop effective models of care that integrate assistive technology, including specific applications for people in rural and remote areas
- increase community awareness and knowledge of the benefits of assistive technology
- reduce social isolation
- reduce the complexities associated with assistive technology applications
- promote innovation
- use inter-disciplinary models of care, and
- measure the impact of assistive technologies to provide evidence of effectiveness and promote transfer of knowledge to other service providers.

Part 5 Carers – palliative and community care

Chapter 21. Carers

... helping carers is one of the best ways of helping someone they are caring for ...
– Queensland Carers Charter

Chapter 3 of this report drew attention to the importance of unpaid and ‘informal’ carers in frameworks of provision of palliative care and home and community care. It outlined State and Commonwealth recognition frameworks and support currently provided for carers. Many submissions highlighted the importance of family and friends as unpaid carers and raised issues and concerns relating to their experiences of providing both palliative care and care for people with disabilities and chronic illnesses at home.

21.1 Profile of carers

21.1.1 Definitions

Carers are “people who provide personal care, support and assistance to people with a disability, medical condition (including terminal and chronic illness), mental illness or frailty due to age”.⁷¹² Generally, people referred to as ‘carers’ are unpaid and are considered to be providing ‘informal care’. They may also be referred to by terms such as ‘informal carer’, ‘family care giver’, ‘lay carer’, and ‘unpaid carer’.

The report of the House of Representatives inquiry into better support for carers, *Who Cares ...?*, noted that becoming a carer is not usually a choice that people make but something that can occur without warning or preparation. It can be a gradual process such that it takes time for the caring role to be recognised.⁷¹³

The issues confronting carers who provide palliative care or care at home for someone with a disability or chronic illness are, in the main, very similar. There are some differences however. For example, undertaking informal palliative care is a role that fewer people have experience of now than might have been the case in the past. The experience of carers undertaking palliative care is likely to be shorter term and more intense than that of other carers. They may have particular needs for grief and bereavement counselling and emotional support. Despite this, the committee has found that most of the issues and challenges facing carers are common across all types of carers.

21.1.2 Numbers

For the purposes of its Disability, Ageing and Carers survey the ABS defines a primary carer as a person aged 15 years and over who “provides the most informal assistance with core activities (communication, mobility and self-care) to a person with a disability or to a person aged 60 years or over”.⁷¹⁴ Using this definition, 12 per cent (or 2.6 million people aged 15 years or over) of Australians had caring responsibilities for a family member or friend with an ongoing disability, long term illness or frailty due to older age.⁷¹⁵

⁷¹² DOHA, *National Respite for Carers Program – Respite Service Providers’ Program Manual*, p.9

⁷¹³ Parliament of Australia, House Standing Committee on Family, Community, Housing and Youth, *Inquiry into better support for carers*, Foreword

⁷¹⁴ ABS, *Caring role brings some families closer together*, Media Release, 20 October 2011, accessed 5 May 2013 from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4436.0Media%20Release12009?opendocument&tabname=Summary&prodno=4436.0&issue=2009&num=&view=>

⁷¹⁵ ABS, *ibid.*

The ABS estimates that 11 per cent of Queenslanders identified themselves as carers in 2009 (494,200) and that nearly a third of these were a primary carer (152,800). In Queensland, 35,164 people received the Australian Government carer payment in December 2011.⁷¹⁶

However “the prevalence of unpaid caring roles for people with a disability or illness is often not recognised by carers themselves, as they may perceive their care activities as simply part of their usual relationship with the person they care for”.⁷¹⁷ It is also possible that the ABS figures exclude many people undertaking palliative care for family and friends as the survey is limited to carers where care is ongoing, or likely to be ongoing, for at least six months.⁷¹⁸

21.1.3 Characteristics

Most primary carers in Queensland live with the person they care for and over two thirds are women.⁷¹⁹ More than 40 per cent of primary carers live outside Queensland’s major urban areas.⁷²⁰ Less than 20 per cent of Queensland’s primary carers are estimated to be employed full time and 35 per cent care for 40 hours or more on average each week. Approximately 35 per cent also report having a disability.⁷²¹ The ABS data does not identify carers by ‘type’, that is, it does not distinguish between people caring for a person with a disability or a person aged 60 years or over or someone who requires palliative care.

Example 4: Queensland’s Primary Carers

Gender	Nearly two-thirds of carers are female
Age	25 per cent are aged 55-64 years
Relationship to care recipient	11 per cent are caring for someone other than a partner, parent or child
Location	43 per cent live outside Queensland’s major cities
Employment status	Only 19 per cent are employed full time
Income sources	Government pension or allowance is the principal source of personal income for 55 per cent
Hours spent caring	35 per cent of carers spend 40 hours or more caring on average each week
Length of time caring	Nearly 60 per cent have cared for more than five years

Source: ABS, *Disability, Ageing and Carers Survey 2009*, Cat. 4430.0 December 2010, State tables for Queensland (electronic data cube).

⁷¹⁶ Department of Human Services, *Administrative Data*, Answer to Question on Notice of Senate Standing Committee on Education, Employment and Workplace Relations EW1043_12, available at http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=eet_ctte/estimates/add_1112/answers/EW1043_12.pdf

⁷¹⁷ Australian Human Rights Commission, *Investing in care: Recognising and valuing those who care – Vol. 1: Research report*, 2013, p.25, available at http://www.humanrights.gov.au/sites/default/files/document/publication/UnpaidCaringVolume1_2013.pdf; and *Carers National Data Repository scoping study: final report*, 2009, Canberra, p.3, available at <http://www.aihw.gov.au/publication-detail/?id=6442468274>

⁷¹⁸ ABS, *Caring role brings some families closer together*

⁷¹⁹ ABS, *Disability, Ageing and Carers Survey 2009*, Cat. 4430.0 December 2010, State tables for Queensland (electronic data cube), Table 32, accessed 8 May 2013 from <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02009?OpenDocument>

⁷²⁰ In Queensland, the ABS area of ‘major cities’ includes Brisbane, most of the Gold Coast and much of the Sunshine Coast.

⁷²¹ ABS, *ibid.*

21.2 Contribution

Unpaid informal carers are major providers of care and support in current frameworks for the care of those who need palliative care or who have a disability or chronic illness. In 2005 Carers Australia commissioned Access Economics to undertake an examination of the amount of informal care being provided in Australia. This work was updated in 2010 and found that unpaid carers now provide 1.32 billion hours of care each year at an estimated annual ‘replacement value’ of \$40 billion. ‘Replacement value’ estimates the resources that would be required to be provided if the unpaid services of carers were no longer available. It is important to note that this excludes a range of other costs that cannot be readily quantified, such as the impact of caring on the health and wellbeing of carers and productivity losses.⁷²² Carers Queensland advised the committee that it is estimated that carers provide 74 per cent of the assistance required by people with disabilities and the frail aged.⁷²³

The Productivity Commission recognised the fundamental role played by carers in the aged care sector both in the provision of care and also the co-ordination of formal care support services in its *Caring for Older Australians* report. It found that carers could be better supported in navigating the care system, gaining the skills needed to care, accessing respite and other supports (including transport and assistive technologies) and participating in the workforce.⁷²⁴

The Productivity Commission noted that its consideration of the needs of carers and proposed reforms were relevant to all carers, including carers of younger people with disabilities. Indeed, in its Disability Care and Support report of the same year, the Productivity Commission again highlighted the importance of informal care in the disability system, noting that “one of the key goals of the NDIS is to relieve the excessive stress that is currently felt by some carers”.⁷²⁵ It also argued that neglecting support for carers (the ‘informal workforce’) was likely to incur ‘substantial’ costs for government later if carers shifted care responsibilities to government. There is, therefore, an economic, as well as social, argument for providing support to carers.⁷²⁶

Carers Queensland noted that changing demographics would increase the need for carers in the future at the same time as the number of people available to provide informal care is decreasing. It brought research conducted for Carers UK to the committee’s attention. This research found that “one in three citizens expect to provide care and support to a family member or friend in their lifetime”. Carers Queensland noted that there was no reason to expect the situation would be any different in Australia.⁷²⁷ Access Economics provides a sobering assessment of the impact of demographic and social trends on the availability of informal care into the future. Projections show that “demand for informal care will substantially outstrip supply by mid-century”.⁷²⁸

Carers Queensland also noted the increasing proportion of carers who are ‘sandwich carers’, caring for an elderly parent and a spouse, child or grandchild.⁷²⁹ Other Queensland service providers noted the decreasing availability of carers.⁷³⁰

⁷²² Access Economics, *The economic value of informal care in 2010*, Report for Carers Australia, October 2010, Foreword and p.ii, available at <http://carersaustralia.com.au/storage/Economic-Value-Informal-Care-Oct-2010.pdf>

⁷²³ Carers Queensland, Submission no. 9, p.4

⁷²⁴ Productivity Commission, *Caring for Older Australians, Report no. 53, Inquiry Report Vol. 2*, 2011, Canberra, pp.325 & 333, available at http://www.pc.gov.au/data/assets/pdf_file/0014/110930/aged-care-volume2.pdf

⁷²⁵ Productivity Commission, *Disability Care and Support, Report no. 54, Inquiry Report Vol. 2*, 2011, Canberra, p.704, available at http://www.pc.gov.au/data/assets/pdf_file/0013/111271/disability-support-volume2.pdf

⁷²⁶ Productivity Commission, *ibid.*, p.725

⁷²⁷ Carers Queensland, *ibid.*, p.5

⁷²⁸ Access Economics, *ibid.*, pp.47–53

⁷²⁹ Carers Queensland, *ibid.*, p.5

⁷³⁰ Professor Janet Hardy and Decima Jones, Submission no. 16, p.4

21.3 Lack of data and research about carers and their needs

The committee was concerned to note that the ABS has recently announced that it will not undertake the Work, Life and Family Survey in 2013 (last done in 2006), which provides time-use information on unpaid caring work. Data available about carers, the hours they work and their contribution is already limited for use in policy and program development and monitoring and will now be reduced just as the burden on carers is likely to increase.⁷³¹

In a scoping study for the Carers National Data repository the Australian Institute of Health and Welfare (AIHW) noted that “research on informal care can at times appear fragmented or limited ... inconsistencies in definitions, measurement and sampling hamper study of the caregiving experience”.⁷³² Other studies note that little research has been done into how best to meet unmet carer needs nor adequate development and evaluation of interventions to assist palliative carers undertaken.⁷³³

A 2009 assessment of the evidence for effective interventions to support carers also noted the need to collect better assessment data on carers and to use this to measure outcomes for carers. It noted that this could then support the benchmarking of carer support services and inform the development of better policy and more effective services.⁷³⁴

The committee notes that the Queensland Government Statistician and the Office of Economic and Statistical Research provide co-ordination and data services to Queensland Government agencies, including specialist statistical consultancy services to advise on the most effective and efficient methods to collect and analyse information.

The committee considers that data about carers is essential to ongoing planning of adequate support for carers whose contribution makes home care possible.

Recommendation 47 – Data on carers

The committee recommends that given the importance of access to reliable data for policy development and planning the Government ask the Government Statistician and the Office of Economic and Statistical Research to ensure that data on carers in Queensland and the hours they work are readily available to government agencies, including data that may be available via Australian Government collections.

⁷³¹ Gittin R, ‘Simple fact is we spend insufficient time with family’, *Sydney Morning Herald*, 13 March 2013, accessed 8 May 2013 from <http://www.smh.com.au/comment/simple-fact-is-we-spend-insufficient-time-with-family-20130312-2fyew.html>

⁷³² AIHW, *Carers National Data Repository scoping study Final report*, 2009, p.3

⁷³³ Hudson P, ‘Home-based support for palliative care families: challenges and recommendations’, *MJA*, September 2003, Vol.179, No.6, pp.S35–S37, p.S36 and Aoun SM, Kristjanson LJ, Currow DC and Hudson PL, ‘Caregiving for the terminally ill: at what cost?’ *Palliative Medicine*, October 2005, Vol.19, No.7, pp.551–5

⁷³⁴ Williams K and Owen A, ‘A contribution to research and development in the carer support sector: Lessons on effective caring’, *Family Matters*, 2009, Vol.82 (Summer), pp.38–46, Australian Institute of Family Studies, <http://www.aifs.gov.au/institute/pubs/fm2009/fm82/kw.pdf>

Chapter 22. Supporting carers

*... many carers are left to struggle with their caring responsibilities ...*⁷³⁵

22.1 Importance of support for carers in the shift to more home and community based care

The recommendations of this report would, if implemented, see a much greater emphasis placed on care in the home and community for palliative and chronic illness patients and people with disabilities. Such a shift would place a greater reliance on the availability of informal care at a time when its availability is decreasing.

The current challenges and concerns for carers will only be magnified by this shift if adequate support for carers is not concurrently considered and resourced. The committee considers that adequate support and efficient structures for carer assistance will need to be put in place in tandem with other recommendations to improve palliative and community care provision.

In particular, a major shift of palliative care effort from hospital to homes and the community will need to be supported by carers, as people cannot die at home or be supported at home in most cases without a carer. A range of research and submissions make similar points, that “... without the support of caregivers, home palliative care would be impossible for many people”.⁷³⁶ In suggesting a shift of emphasis in palliative care from the hospital setting to the home, it must be recognised that this will not be possible without the person having a primary carer, who will probably be unpaid.

Research into the impacts of the caregiving role shows the “... considerable commitment required by those who assume a home caregiver role, and health professionals who support home care need to appreciate this level of commitment and the stress that it may engender”.⁷³⁷ Complex care can be involved for the carer of a terminally ill patient, which may require advanced skills such as opioid administration and symptom management.⁷³⁸

When briefing the committee, Professor Patsy Yates noted that the availability of carers would become an increasing challenge for palliative care services. She explained that:

*family structures are changing. In the past we would have had people at home maybe to provide home support. We know there are many more single person households now and that the support for people in the community to die often relies in large part on them having a carer, and that is becoming increasingly difficult with our current family structures.*⁷³⁹

In evidence to the Senate inquiry into palliative care in 2012, a palliative care provider in Victoria noted that 26 per cent of its clients had no carer and the ‘great worry’ this was, with the limited options available to these clients unless they could afford to pay a live-in carer.⁷⁴⁰

Palliative Care Australia told the Senate inquiry into palliative care last year that:

*regardless of the place of death, it is estimated that up to 90% of people in the terminal phase of a life threatening illness spend the majority of their time at home supported by a carer.*⁷⁴¹

⁷³⁵ Sarah Walbank, Policy and Research Officer, Carers Queensland, *Public Hearing Transcript*, 24 August 2012, p.5

⁷³⁶ Hudson P, ‘Home-based support for palliative care families: challenges and recommendations’, p.S35

⁷³⁷ Hudson P, *ibid.*, p.S35

⁷³⁸ Hudson P, *ibid.*, p.S35

⁷³⁹ Professor Patsy Yates, *Public Briefing Transcript*, 20 June 2012, p.2

⁷⁴⁰ Eastern Palliative Care submission, quoted in the Senate Community inquiry, *Palliative care in Australia*, p.62

⁷⁴¹ PCA, quoted in the Senate Community inquiry, *Palliative care in Australia*, p.61

Professor David Currow advised the Senate committee that ‘having someone who identifies as a primary care giver is the most important predictor of home-based care’.⁷⁴² Submissions noted the importance of having a live in carer in order to be able to provide palliative care in the home. Eastern Palliative Care told the Senate inquiry into palliative care that they needed a carer to be present for a palliative care service to be able to provide pain relief.⁷⁴³ In 2003, it was already being noted that ‘...families are increasingly replacing skilled health workers in the delivery of unfamiliar complex care’.⁷⁴⁴

Professor Currow also drew attention to the significant implications of taking on a palliative care role and advised the committee “Let’s not romanticise the role”.⁷⁴⁵ In hindsight, many carers indicated that they would not take on such a role again.⁷⁴⁶ In assessing the challenges of home-based palliative care, Peter Hudson counselled that “advocacy for home care should not put pressure on families ...”⁷⁴⁷ Professor Currow also noted that there may be differences of opinion between carer and patient about the best place for care.⁷⁴⁸

The committee would be concerned if its recommendations encouraged the pursuit of government savings at the cost of placing overwhelming and unsustainable burdens on individuals and families.

22.2 Carer needs

Carers face a range of challenges. These were raised in submissions and evidence provided to the current inquiry, and have also been canvassed in a range of reports and inquiries. Many carers experience health, social, emotional, economic and employment disadvantages.⁷⁴⁹

The House of Representatives inquiry report *Who cares ...?* lists the problems faced by carers, which include:

- lack of recognition of the carer role and contribution
- difficulties accessing information on supports and services, lack of assistance in developing skills and capacity building
- financial stresses
- dissatisfaction with community care systems (which carers find to be complex, inflexible, costly to access and lacking in quality)
- lack of choice due to lack of respite
- physical, emotional and social impacts.

In its *Carers National Data Repository scoping study: final report*, the Australian Institute of Health and Welfare (AIHW) added to this list workforce participation and stress and burden.⁷⁵⁰

Submissions to the committee raised similar issues and concerns for carers in Queensland, indicating that carers:

- are at risk of mental health problems
- confront financial issues
- need better workplace support and

⁷⁴² Professor David C. Currow, quoted in the Senate Committee inquiry, *Palliative care in Australia*, p.64

⁷⁴³ Eastern Palliative Care submission, quoted in the Senate Committee inquiry, *Palliative care in Australia*, p.63

⁷⁴⁴ Aoun *et al.*, ‘Caregiving for the terminally ill: at what cost?’, p.551

⁷⁴⁵ Professor David C. Currow, Submission no. 62, p.6

⁷⁴⁶ Professor Katherine Clark, Catholic Health Australia, quoted in the Senate Committee inquiry, *Palliative care in Australia*, p.64

⁷⁴⁷ Hudson P, ‘Home-based support for palliative care families: challenges and recommendations’, p.S36

⁷⁴⁸ Professor David C. Currow, *ibid.*, p.6

⁷⁴⁹ Carers Queensland, Submission no. 9, p.4

⁷⁵⁰ AIHW, *Carers National Data Repository scoping study Final report*, p.3

- would be better supported through the adoption of case management approaches with improved co-ordination.

In particular, Carers Queensland noted that carers are estimated to have the lowest collective wellbeing of the population. Many carers experience health, social, emotional, economic and employment disadvantages.⁷⁵¹ There can be profound impacts on families undertaking palliative care at home and “relatives of cancer patients may experience as many (if not more) psychological problems as the patient”.⁷⁵² They are also likely to experience health problems.⁷⁵³

Carers of children requiring palliative care have particular needs and there are additional impacts on siblings and the rest of the family. Children with a life-limiting condition may need palliative care over longer timeframes with greater unpredictability.⁷⁵⁴

Review of the research on the impact of care giving on palliative carers shows:

*Considerable evidence in the literature that the burden of caregiving is adversely affecting family caregivers who lack adequate resources or who are insufficiently prepared for this new complex role.*⁷⁵⁵

A survey of carers receiving the Australian Government Carer Payment and/or Carer Allowance found that carers had high rates of mental health problems and that almost twice as many carers were in poor physical health than the general population.⁷⁵⁶

Evidence from a group of about 15 carers in Bulimba who meet monthly to support each other made it clear to the committee that it is difficult for carers in Queensland to obtain information about the support available for carers, including how to access respite care, even when a carer is already receiving some in-home help. They also noted the problems of duplication in assessments for eligibility and the difficulties of dealing with different service providers with different procedures.

Carers Queensland made a number of recommendations for better support for carers in its submission to the committee. These included:

- person-centred planning, the right of a carer to an assessment, integrated and holistic assessment, planning, delivery and review
- funding of carer-specific early interventions
- portable entitlement vouchers that carers can use to purchase respite
- enhanced advocacy support services and
- an early intervention service to help carers ‘preparing to care’ after hospital discharge.⁷⁵⁷

The Australian Human Rights Commission listed the mechanisms that can be used to support carers in its recent report *Investing in Care: Recognising and valuing those who care*. These mechanisms include:

- legislative mechanisms
- carer support payments and services
- work related arrangements and initiatives and
- mechanisms within retirement income and savings arrangements.⁷⁵⁸

⁷⁵¹ Carers Queensland, Submission no. 9, pp.4 & 7

⁷⁵² Hudson P, *ibid.*, p.S35

⁷⁵³ Hudson P, *ibid.*, p.S36

⁷⁵⁴ Fiona Engwirda, Submission no. 70 p.13

⁷⁵⁵ Aoun *et al.*, *ibid.*, p.551

⁷⁵⁶ Edwards B, Higgins DJ, Gray M, Zmijewski N and Kingston M, *The nature and impact of caring for family members with a disability in Australia*, Research Report No. 16, 2008, A collaborative project between the Australian Institute of Family Studies and the FAHCSIA, pp.xiii–xiv, available at

<http://www.aifs.gov.au/institute/pubs/resreport16/report16pdf/rr16.pdf>

⁷⁵⁷ Carers Queensland, *ibid.*, pp.12–3

The Carers Group Bulimba recommended that an individual case management approach would “greatly alleviate some of the anxieties that exist ...” for carers and that a streamlined assessment process for eligibility for services and support would also assist carers.⁷⁵⁹

As noted earlier, research and evaluation of appropriate interventions to effectively assist and support carers is limited. There are a number of areas, however, where the committee believes changes can usefully be made to better support carers and their critical role.

22.3 Greater recognition

While there is Commonwealth and State legislation that recognises the important role of carers, as outlined in Chapter 3, the Australian Human Rights Commission notes that these frameworks do not include enforceable obligations. Legislative and planning frameworks for recognition are now in place but a range of other issues of adequate recognition of carers remain unaddressed. Needs of carers are ‘ignored’ across a range of policy frameworks such as those relating to taxation, income support, employment and labour market. Carers are ‘marginalised’ within the social welfare system.⁷⁶⁰

Many carers note that they are often excluded from consultation and decision making processes concerning care.⁷⁶¹ The Senate inquiry into palliative care noted that, as providers of ‘informal care’, carers of palliative patients are separated from the professional palliative care workforce “because they are often unpaid, untrained volunteers who are also usually close family members of patients”.⁷⁶²

Service providers should consult and work with carers and this would be assisted by ensuring that carers are recognised in service agreements and funding models. Carers Queensland advocated person-centred planning and flexible service delivery that involves carers as real partners in the work of caring. A recent Carer’s Queensland survey showed nearly 90 per cent of carers were interested in participating in consumer directed care. Such a framework would assist in building and maintaining carer resilience.⁷⁶³

Evaluation the use of consumer-directed care respite care package for carers of older people showed considerable benefits for carers in being able to plan and focus on themselves rather than the person they were caring for. The evaluation reported that many carers felt that “they were being recognised and valued as carers – often for the first time.”⁷⁶⁴

The committee notes the importance of carers being treated as ‘genuine partners’ in care provision.

Recommendation 48 – Service providers to consult with carers

The committee recommends that the Minister for Communities, Child Safety and Disability Services ensure that service providers are required to consult with carers about the delivery of services.

⁷⁵⁸ Australian Human Rights Commission, *Investing in Care: Recognising and valuing those who care*, p.6

⁷⁵⁹ The Carers’ Group Bulimba, Submission no. 34

⁷⁶⁰ Aoun *et al.*, ‘Caregiving for the terminally ill: at what cost?’, p.553

⁷⁶¹ Carers Queensland, *ibid.*, p.9

⁷⁶² Senate Committee inquiry, *Palliative care in Australia*, p.61

⁷⁶³ Carers Queensland, *ibid.*, p.12

⁷⁶⁴ KPMG, *Evaluation of the consumer directed care initiative – final report*, DOHA, 2012, Canberra, p.3, available at <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-cdc-evaluation.htm>

Recommendation 49 – Carer involvement in policy development

The committee recommends that the Minister for Communities, Child Safety and Disability Services ensure that policy development and implementation supports the role of carer by consulting with carer organisations on the development of any legislation, policy or program guidelines.

22.4 Improved access to better information

A significant issue for carers is access to timely and appropriate information and support and the additional burden placed on carers and families of coordinating support and services. The information needs of carers require adequate resourcing and must be responsive to carer and community diversity.⁷⁶⁵ Submissions to the committee from parents noted that hospitals did not provide connections to information about assistance and that co-ordination of support and assistance was difficult with little help provided.⁷⁶⁶ One highlighted the need for specialised case workers to work with a family.⁷⁶⁷

Carers Queensland advocated focusing on early intervention for the provision of carer services and support. “Current provision of services for informal caregivers has been described as ‘crisis intervention’, as it is only in crisis situations of imminent or apparent break down that services respond.”⁷⁶⁸ Carers Queensland advised the committee that the current focus on the provision of support to carers at the point of ‘crisis’ simply results in the need for more ‘crisis services’ as other carers miss out on assistance and support and may then find themselves in crisis situations and unable to cope.⁷⁶⁹ Prevention and early intervention have the potential to reduce longer term demand for crisis responses, reduce the number of people who ‘fall through the cracks’, and potentially assist a larger number of people.⁷⁷⁰

A particular need for palliative carers is “information on how to provide practical care ... how to ease a patient’s discomfort, what to expect, ... where and how to acquire practical aids...”⁷⁷¹ The committee considers that this practical information and training should be a role of palliative care service providers (see Chapters 12 and 13).

The committee notes that the Senate inquiry into palliative care recommended that a review of *CareSearch* site be undertaken, ahead of improvements in the provision and timeliness of information to palliative care patients.⁷⁷²

Recommendation 50 – Information for carers

The committee recommends that the Minister for Communities, Child Safety and Disability Services, in developing the information service recommended in Recommendation 42, specifically include information to assist carers.

22.5 Better assessment

Carers Queensland states that carers do not feel adequately supported in their role⁷⁷³ and advocates for the development of a carer specific assessment and early intervention services. It argues that

⁷⁶⁵ Senate Committee inquiry, *Palliative care in Australia*, p.67

⁷⁶⁶ Fiona Engwirda, Submission no. 70, pp.6 & 15 and Brett and Louise Carter, Submission 30, p.3

⁷⁶⁷ Brett and Louise Carter, *ibid.*, p.4

⁷⁶⁸ Aoun *et al.*, ‘Caregiving for the terminally ill: at what cost?’, p.553

⁷⁶⁹ Carers Queensland, Submission no. 9, p.6

⁷⁷⁰ Carers Queensland, *ibid.*

⁷⁷¹ Aoun *et al.*, *ibid.*, p.552

⁷⁷² Senate Committee inquiry, *ibid.*, p.76

carer assessments should be separate to the assessment of the person receiving care and enable carer specific support services to be identified.⁷⁷⁴ Early intervention services would assist individuals new to the caring role and could include information and advice, timely referral, training and education and locally provided respite care. Carers Queensland believes these services should be available in the community, and following discharge from hospital after an acute or critical health episode.⁷⁷⁵

A submission from a parent indicated that the lengthy assessment process for access to respite was a problem.⁷⁷⁶ The lengthy assessment process for access to respite was not only an issue for the families of children requiring palliative care. Professor Vora also noted the long time that carers can spend waiting for an assessment to be made by Disability Support Queensland (now the Department of Communities, Child Safety and Disability Services) only to be advised that they are not eligible. He said that some patients die while waiting for assessment to be completed, adding to the trauma for families.⁷⁷⁷

Section 4 of the *Queensland Carers Charter* states:

*The importance of carers' work means the role of carers should be recognised by including carers, or their representative bodies, in the assessment, planning, delivery and review of services affecting carers.*⁷⁷⁸

While carers of people eligible for Queensland community care services may also receive counselling, support, information, advocacy and respite care, unlike other jurisdictions, there is no clear requirement to assess carers' needs for services or guidance on what an assessment should consider.⁷⁷⁹ Specialist palliative care services also need to ensure that their delivery of services recognise the importance of carers' work and the importance of assessing carer needs at the same time as those of the patient.⁷⁸⁰ The committee understands that the carer may also be a recipient of Community Care services and should therefore participate in an assessment.

Improved and timely assessment, with early intervention, would then support the implementation of case management for carers and those they care for. Case management has been addressed in more detail in Chapter 23. The clinicians from the Mater Health Services related their experience that carers are relieved when they have a contact person for advice, support and education, to whom they do not have to repeat the patient's story.⁷⁸¹

The committee acknowledges the vital role carers play in supporting people to remain in the community and at home and the need to adequately assess carer needs in a timely way if this role is to continue.

⁷⁷³ Carers Queensland, *ibid.*, p.7–10

⁷⁷⁴ Carers Queensland, *ibid.*, p.12

⁷⁷⁵ Carers Queensland, *ibid.*, p.13

⁷⁷⁶ Fiona Engwirda, *ibid.*, pp.6 & 15

⁷⁷⁷ Professor Rohan Vora, Submission no. 73, p.7 and pp.7–8

⁷⁷⁸ *Carers (Recognition) Act 2008 (Qld)*, Sch – The Queensland Carers Charter, available at <http://www.legislation.qld.gov.au/LEGISLTN/ACTS/2008/08AC070.pdf>

⁷⁷⁹ DCCSDS, *Manual for Queensland Community Care Services*, p.8

⁷⁸⁰ Professor Katherine Clark, Catholic Health Australia, quoted in the Senate Committee inquiry, *Palliative care in Australia*, p.64

⁷⁸¹ Professor Janet Hardy and Decima Jones, Submission no. 16, p.7

Recommendation 51 – Carer’s needs assessment – Queensland Community Care

The committee recommends that the Minister for Communities, Child Safety and Disability Services direct the Department of Communities, Child Safety and Disability Services to include in service agreements with providers of Queensland Community Care Services or in guidelines for service providers a requirement to individually assess a carer’s needs.

Recommendation 52 – Carer’s needs assessments – palliative care

The committee recommends that the Minister for Health ensure that Queensland Health’s service agreements with Hospital and Health Services (HHS) require specialist palliative care services to assess carer needs and that any service agreements between a HHS and service provider include a requirement to assess carer needs.

22.6 Better access to respite

A high priority in improving support for carers is the provision of flexible, adequate respite for carers. There is no adequate, single source of respite services for carers of someone who has a terminal illness. As noted in Chapter 3, some carers received funding supplementing HACC before the segmentation by age; others may be eligible for access to respite under Queensland Community Care. Different sources of funding “increases complexity and reduces flexibility of care arrangements”. This adds to delays and leads to unnecessary hospital admissions.⁷⁸² With the segmentation of care responsibilities between the Australian and Queensland Governments on the basis of age, carers of people aged under 65 (or under 50 if Aboriginal or Torres Strait Islander) no longer have access to Australian Government funded respite services.

Submissions noted the importance of respite services, and particularly funded overnight respite nursing services, to support palliative care in the community and home. Day time home nursing services do not always have the resources to cover the costs of overnight care. Hopewell Hospice noted its experience that “once families are unable to cope with night nursing needs hospital stay becomes the only option”.⁷⁸³ The clinicians from the Mater Health Services advised the committee that “the availability of respite care, especially overnight, has been identified as a key element to supporting patients to die at home.”⁷⁸⁴ Submissions also noted that additional carer support reduces carer stress.⁷⁸⁵

In its report *Caring for the Community*, the ABS reported that there were 98,300 carers in Australia who indicated a need for respite care but that most of those needing respite (64 per cent) had never used respite care services.⁷⁸⁶ The survey of carers receiving carer payments or allowances found that few families used respite care (13 per cent) and that three out of five of those who did, used respite for less than 20 hours per month.⁷⁸⁷ Palliative Care Queensland noted that families caring for children with a life-limiting condition need additional respite assistance.⁷⁸⁸

Submissions that told the committee about respite services were based on experience prior to the segmentation of care arrangements in July 2012. The committee heard evidence that respite is hard

⁷⁸² Anglicare Southern Queensland, Submission no. 72, p.5

⁷⁸³ Hopewell Hospice Services Inc., Submission no. 27, p.8

⁷⁸⁴ Professor Janet Hardy and Decima Jones, Submission no. 16, p.5

⁷⁸⁵ Blue Care and UnitingCare Health, Submission no. 24, p.18

⁷⁸⁶ ABS, *Caring role brings some families closer together*

⁷⁸⁷ Edwards *et al.*, *The nature and impact of caring for family members with a disability in Australia*, p.xvi

⁷⁸⁸ PCQ, Submission no. 74, p.11

to access from Queensland Community Care. A parent who cared at home for a son with a terminal illness related how the family had not received respite care.⁷⁸⁹

Submissions to the inquiry indicated that the respite services provided or funded by the Queensland Government are limited, difficult to qualify for, and inflexible. Long times for assessment of eligibility need to be addressed, particularly for carers of palliative patients, and also for all carers. In its submission to the inquiry, Palliative Care Queensland told the committee that one of the principal issues in Queensland's poor performance in relation to palliative care was insufficient access to respite services.⁷⁹⁰ Queensland Health acknowledged the importance of respite care to providing palliative care in the community and the limited options available to carers and families.⁷⁹¹

Carers Queensland emphasised that services should work in partnership with carers and the person they care for, whether their needs are for routine respite care or respite for more challenging care, such as palliative care.⁷⁹²

Again, the committee's view is that a shift to home-based care needs to be adequately resourced to provide support for carers. The committee considers the most important practical component of support for carers is access to flexible and adequately funded respite care.

Recommendation 53 – Carer's respite

The committee recommends that the Minister for Communities, Child Safety and Disability Services, in consultation with the Minister for Health, develop an adequate, single program of respite support for carers that provides for streamlined access based on flexible options for carers for use across a range of respite types (e.g. in-home and centre-based, both day and overnight).

22.7 Financial assistance

Submissions and evidence to the inquiry made clear the significant financial impacts that caring for someone with a disability or terminal illness can have. The costs of special equipment and medications and limitations on a carer's capacity to undertake paid work have a negative impact on family finances and financial security. In a submission to the inquiry a parent who cared for a child with a terminal illness and who continues to care for a child with a disability, outlined in detail the financial situation the family was placed in as a result of the requirements of caregiving.⁷⁹³

An assessment of the costs of caregiving for the terminally ill noted that "the economic impact of day-to-day family involvement in living with cancer can be profound ..."⁷⁹⁴ The clinicians at the Mater Health Services listed the additional costs for carers as: "equipment hire, medical supplies, extra washing, parking and transport to appointments, cost of medications, and the contribution to domiciliary nursing services ...". These costs are exacerbated as disease trajectories lengthen.⁷⁹⁵ Fiona Darroch-Speedie, who cared for her father at home as he died of pancreatic cancer, outlined the costs to the family of the modifications, equipment, supplies and nursing assistance required to

⁷⁸⁹ Tracy and Warren Taprell, Submission no. 28, p.3

⁷⁹⁰ PCQ, *ibid.*, p.12

⁷⁹¹ Queensland Health, Submission no. 35, pp.11–12

⁷⁹² Carers Queensland, Submission no. 9

⁷⁹³ Fiona Engwirda, Submission no. 70, p.8

⁷⁹⁴ Aoun *et al.*, 'Caregiving for the terminally ill: at what cost?', p.552

⁷⁹⁵ Professor Janet Hardy and Decima Jones, *ibid.*, p.6

support him at home. At the same time, Ms Darroch-Speedie lost her capacity to earn additional income at night and on the weekend through her second job due to her role as primary carer.⁷⁹⁶

As outlined in Chapter 3, the Australian Government provides income support for carers through its Carer Payment and Carer Allowance as well as the Carer Supplement. The Carer Payment was increased in 2009 and is means tested on the income and assets of the carer as well as those of the person receiving care. The Carer Allowance is provided on the basis of the needs of the person being cared for and is not means tested. The committee noted that the Australian Human Rights Commission has suggested that income testing arrangements be reviewed, as well as the number of hours allowed for work, education, or training while receiving the Carer Payment.⁷⁹⁷

The committee notes the importance of Australian Government income support for carers and their financial situation while recognising that this is outside the responsibility of the Queensland government. The committee also notes, however, the importance of ensuring that Queensland government programs provide additional assistance to carers, such as equipment and medical supplies, are adequately funded. Evidence to the committee indicates that these services can go some way to alleviating the financial burdens on carers, but may not be sufficiently funded to meet current demand.

22.8 Workforce flexibility

Carers would benefit from flexible employment arrangements that provide more options for combining paid employment and care giving. In addition to suggesting changes to the *Fair Work Act 2009* (Cwlth) and National Employer Standards, both Australian Government responsibilities, the Australian Human Rights Commission report *Investing in care: Recognising and valuing those who care* recommended that employers should consider implementing mechanisms to support unpaid carers in the workplace, such as:

- adopting an integrated carer strategy
- providing information and support services to carers
- offering flexible hours and leave arrangements
- undertaking job redesign to accommodate caring commitments
- implementing employment re-entry strategies during and after caring responsibilities.⁷⁹⁸

The report included a toolkit for workplaces, with practical suggestions and examples of different kinds of workplace mechanisms to support carers. The Australian Government has also recently endorsed a new initiative 'Care Aware Workplaces' which aims to improve workplace arrangements for unpaid carers.⁷⁹⁹ Workplaces are asked to register to commit to better understanding the needs and values of carers and to encourage flexible workplace arrangements for them and are acknowledged as a carer friendly workplace.

⁷⁹⁶ Fiona Darroch-Speedie, Submission no. 40, p.5

⁷⁹⁷ Australian Human Rights Commission, *Investing in care: Recognising and valuing those who care*, pp.45 & 46

⁷⁹⁸ Australian Human Rights Commission, *ibid.*, p.13

⁷⁹⁹ Care Aware, *National Carer Awareness Initiative*, Care Aware Workshop, accessed 10 May 2013 from <http://careaware.com.au/workplaces>

Recommendation 54 – Carers – workplace flexibility

The committee recommends that the Queensland government work toward implementation in all Queensland government and local government workplaces, integrated carer strategies, and provide information and support services to carers, offer flexible hours and leave arrangements, undertake job redesign to accommodate caring commitments and implement employment re-entry strategies during and after caring responsibilities.

Recommendation 55 – Carers support – national

The committee recommends that the Government raise the importance of recognising carers' needs for flexibility in the workplace with the COAG Select Council on Workplace Relations and encourage implementation of additional strategies to support employed carers.

22.9 Bereavement support and counselling

No one ever told me that grief felt so like fear. – C.S. Lewis

A range of evidence to the committee noted the importance of bereavement support for carers. This is also supported in research on carer needs.

The clinicians at the Mater Health Services described the emotional strains on palliative carers, and the loss of self-identity and social isolation that can occur.⁸⁰⁰ In her submission, Julie Sutherland, a counsellor at a specialist palliative care service, outlined the impact of unmet bereavement care needs. These include “increased susceptibility to physical morbidity, social isolation, financial disadvantage, psychological distress and needs of caregivers at least equal to or greater than the patients themselves”.⁸⁰¹ Hopewell Hospice drew attention to children’s needs for assistance with grief and loss when a family member is dying, noting that these needs are ‘often neglected’.⁸⁰² Yeshe Khadro, Karuna Hospice, told the committee of the importance of facilitating spiritual care for people, particularly those who do not have a connection with a formal faith.⁸⁰³

Palliative Care Australia maintains that bereavement care is a cornerstone of quality palliative care.⁸⁰⁴ The importance of bereavement care is recognised in the World Health Organisation definition of palliative care and is a service requirement in the Queensland Clinical Service Capability framework.⁸⁰⁵

Ipswich Hospice care described its bereavement services in its submission. Bereavement support is provided by Hilda’s House, a service largely run by specially trained volunteers which provides one-on-one counselling and a variety of grief support groups, including groups for children.⁸⁰⁶ Hopewell Hospice also provides bereavement support and an illness support program.⁸⁰⁷

⁸⁰⁰ Professor Janet Hardy and Decima Jones, Submission no. 16, p.6

⁸⁰¹ Julie Sutherland, Submission no. 57, p.1

⁸⁰² Hopewell Hospice Services Inc., Submission no. 27, p.7

⁸⁰³ Yeshe Khadro, Chief Executive Officer, Karuna Hospice, *Public Hearing Transcript*, 24 August 2013, p.16

⁸⁰⁴ PCA, *Palliative Care Service Provision in Australia: A Planning Guide*, as quoted in Professor Liz Reymond, Submission no. 11, p.14

⁸⁰⁵ Noted by Ipswich Hospice Care Inc., Submission no. 59, p.6

⁸⁰⁶ Ipswich Hospice Care Inc., *ibid.*, p.6

⁸⁰⁷ Deidre Hanna, Submission no. 49, p.1

A number of submissions, however, noted the ‘paucity’ of specialised palliative care bereavement counsellors in Queensland Health palliative care services.⁸⁰⁸ Ms Sutherland pointed out that there is “no single, established agency” in Queensland for the provision of bereavement counselling and that “often bereavement follow up just simply does not occur.”⁸⁰⁹ A parent who cared for a terminally ill child told the committee that after her son died all services stopped “... that is something that is hard for a grieving family to accept”.⁸¹⁰

The report of the Senate inquiry into palliative care recognised the importance of bereavement support for families and carers and commented that provision should be a priority. It also noted evidence that there were public health ramifications of bereaved Australians with “significant morbidity associated with being a carer”.⁸¹¹ The inquiry report recommended that governments work together to fund minimum levels of bereavement services.

The provision of quality bereavement support is an essential part of the provision of palliative care services before and after the death of the person being cared for. Under the CSCF, specialist palliative care services must include a ‘dedicated bereavement counsellor’ to be assessed as a level 5 and 6 service.

The committee has already made recommendations relating to the resourcing and service capacity of specialist palliative care services. Given the importance of support for carers, and that emotional and spiritual care is a core element of palliative care, the committee believes that bereavement and counselling services are essential.

Recommendation 56 – Specialist bereavement services

The committee recommends that the Minister for Health ensure that Hospital and Health Service service agreements include recognition that quality palliative care services, particularly in higher level services (in the Clinical Services Capability Framework), should include specialist bereavement services.

Recommendation 57 – Counselling services for carers

The committee recommends that the Minister for Communities, Child Safety and Disability Services ensure that relevant service agreement contracts with service providers include the provision of counselling services for carers.

22.10 Capacity building – training and support for carers

Evidence to the committee indicated concerns about the capacity of carers and recognition of their training needs. The Senate inquiry into palliative care noted comments from service providers that the knowledge of how to support people with palliative care needs is not as widespread as it used to be and carers need more support in this regard.⁸¹² Carers for people with a disability or chronic illness do not always have access to how to care safely and this can lead to injuries for carers.⁸¹³

⁸⁰⁸ Professor Liz Reymond, Submission no. 11, p.14; and Julie Sutherland, Submission no. 57, p.1

⁸⁰⁹ Julie Sutherland, *ibid.*, p.2

⁸¹⁰ Tracy and Warren Taprell, Submission no. 28, p.3

⁸¹¹ Professor Katherine Clark, Catholic Health Australia, quoted in the Senate Committee inquiry, *Palliative care in Australia*, pp.64 & 76–77

⁸¹² Senate Committee inquiry, *Palliative care in Australia*, p.63

⁸¹³ Carers Queensland, *Public Hearing Transcript*, 24 August 2012, p.5

In its report on the economic value of informal care, Access Economics noted the importance of providing carers with access to education and training programs on how to care, and on the care recipient's particular condition, in improving the physical and mental health of carers.⁸¹⁴ The report noted that there is a 'substantial investment' in training provided to paid carers but in contrast there was 'relatively little' provided for unpaid carers who were equally in need of such training.⁸¹⁵

Professor Liz Reymond drew the attention of the committee to the Brisbane South Palliative Care Collaborative's use of the Australian Government's 'Caring Safely at Home' by as part of its activities in capacity building for carers.⁸¹⁶ This is a standardised education and resource package designed to improve the capacity and confidence of lay caregivers to manage subcutaneous medications.⁸¹⁷

The committee has recommended in Chapter 13 that specialist palliative care services include support and training for carers at home.

Recommendation 58 – Carers – guidance and training on how to care safely and self-care

The committee recommends that the Minister for Communities, Child Safety and Disability Services ensure that relevant agreements with service providers and service guidelines require providers to offer practical training and guidance about how to care safely and on self-care for carers.

Professor Reymond also highlighted the importance of volunteers in palliative care in providing respite for carers and social contact for patients. She recommended that Level 6 specialist palliative care services should be funded to support a paid and trained volunteer co-ordination role.⁸¹⁸ The Senate inquiry into palliative care also noted the need for funded volunteer support programs and training for palliative care volunteers.⁸¹⁹ The committee believes that there is also a need for volunteer programs to support other carers in similar ways and that service providers may also need to be resourced for volunteer co-ordination and training.

Recommendation 59 – Specialise palliative care services – volunteer co-ordinators

The committee recommends that the Minister for Health ensure that appropriate mechanisms are in place to ensure that Level 5 and 6 specialist palliative care services (in the Clinical Services Capability Framework) are resourced to engage a person to train and coordinate volunteers to provide services such as in-home social contact and respite for carers.

⁸¹⁴ Access Economics, *The economic value of informal care in 2010*, pp.36–7

⁸¹⁵ Access Economics, *ibid.*, pp.38–9

⁸¹⁶ Professor Liz Reymond, *ibid.*, p.14

⁸¹⁷ CareSearch, *Caring Safely at Home Project – Queensland*, accessed 10 May 2013 from <http://www.caresearch.com.au/caresearch/tabid/2145/Default.aspx>

⁸¹⁸ Professor Liz Reymond, *ibid.*, p.19

⁸¹⁹ Senate Committee inquiry, *ibid.*, p.68

Part 6 Collaboration and co-operation between services – opportunities for reform

Chapter 23. Improving collaboration and co-ordination

... services tend to be defined according to service needs and budgets rather than patient needs.⁸²⁰

23.1 Introduction

The committee's terms of reference require it to consider opportunities for reforms to improve collaboration and co-operation between chronic, disability and other health services. Ensuring that health and other human services are co-ordinated and work collaboratively to the benefit of patients and clients has been the subject of research and published articles since at least the 1970s.⁸²¹ The committee has heard evidence about a range of issues and problems that arise for patients, clients and carers because of a lack of co-ordination and collaboration, and has made some recommendations for improvement.

This chapter discusses some changes that the committee considers could result in more person-centred care. The committee recognises that problems arising from lack of collaboration and co-ordination will not be resolved by simply encouraging more collaboration and better co-ordination. Instead, transformative changes are required to modify the way that services operate. One important potential tool to reform and transform collaboration and co-ordination is the use of eHealth, which is discussed below.

Common themes in submissions and oral evidence were the need to improve discharge planning and case management so that people do not 'fall between the cracks' and are not required to co-ordinate the sometimes complex network of services and agencies they need. These issues are discussed below, along with the potential of eHealth as a tool to promote and enable collaboration and co-ordination.

23.1.1 Government perspectives

The Department of Communities, Child Safety and Disability Services submission noted that people with a disability experience poor health outcomes. The Department said it was encouraged that the committee was exploring opportunities for better co-ordination and collaboration across disability and health services. The Department submitted that:

One of the key issues requiring attention in any future considerations is in relation to greater clarity about the responsibility between community care and palliative care services.

Clients eligible for community care services, who require palliative care, can continue to receive community care's basic maintenance and support services, subject to their priority of need and the capacity of the service provider. Support is available to carers of

⁸²⁰ St Vincent's Hospital Brisbane, Submission no. 44, p. 6

⁸²¹ For example, Gilbert N and Specht H, 'Quantitative Aspects of Social Service Coordination: is more better?', *Administration in Social Work*, 1977, Vol.1, No.1, pp.53–62; Birnbaum H, Burke R, Swearingen MP and Dunlop B, 'Implementing Community-Based Long-Term Care: Experience of New York's Long Term Home Health Care Program', *The Gerontologist*, 1984, Vol.24, No.4, pp.380–6; Addington-Hall JM, MacDonald LD, Anderson HR, Chamberlain J, Freeling P, Bland JM, Raftery J, 'Randomised controlled trial of effects of coordinating care for terminally ill cancer patients' *British Medical Journal*, November 1992, Vol.305; No.6865, pp.1317–22; Miller AR, Condin CJ, McKellin WH, Shaw N, Klassen AF, Sheps S, 'Continuity of care for children with complex chronic health conditions: parent's perspectives' *BMC Health Services Research*, December 2009, Vol.9, No.242

*eligible clients. However, specialist palliative care services are considered outside the scope of Queensland community care.*⁸²²

The establishment of Hospital and Health Services (HHS) is a potential driver of improvements in collaboration and co-ordination. Hospital and Health Services have obligations to engage with clinicians and the community and could have a significant impact if HHS engagement with GPs, other health providers and residential aged care facilities is effective and focused on collaboration and co-ordination to deliver person-centred care.

Queensland Health's submission noted that the establishment of HHS created opportunities to meet community needs and provide:

*a platform to enable better co-ordination and integration of care between public and private services..., an opportunity to build a stronger interface between the health, aged care and disability services sectors. ... (and) build collaborative and formal partnerships between palliative care providers and other community care providers to provide efficient and seamless community care round-the-clock.*⁸²³

The functions of HHS are set out in the *Hospital and Health Boards Act 2011*. Those functions or requirements that are particularly relevant to improving collaboration and co-operation include that HHS:

- contribute to and implement Statewide service plans that apply to the HHS and undertake further service planning that aligns with the Statewide plans
- develop and publish a clinician engagement strategy, develop local clinical governance arrangements, cooperate with other providers of health services and with local primary health care services
- seek to agree on a protocol with local primary health care organisations to promote co-operation between the HHS and those organisations in the planning and delivery of health services, and
- consult with health professionals, health consumers and members of the community about the provision of health services.⁸²⁴

The Minister for Health acknowledged that there has been some fragmentation in health services, and that co-ordination could be improved.⁸²⁵ He said that the way forward

*... is to ensure far better cooperation and coordination between the various agencies that deliver at the moment, that being the hospital and health services working with the Medicare Locals and the way they then go out into the community if they are purchasing services from someone else.*⁸²⁶

The challenge is to plan for person-centred services, at state-wide, regional and local levels, and to implement reforms that can overcome barriers to collaboration and co-ordination.

23.1.2 Recommendations to support improved co-ordination

Elsewhere in this report the committee has made recommendations that, if implemented, would contribute to improved co-ordination and collaboration in the delivery of services. The committee recognises however that implementation of those recommendations will not be sufficient to achieve truly person-centred treatment and care. The committee's recommendations that are expected to have some impact on co-ordination, if implemented, are summarised below:

⁸²² DCCSDS, Submission no. 76, p.9

⁸²³ Queensland Health, Submission no. 35, p.14

⁸²⁴ Queensland Health, *ibid.*, pp.13–4

⁸²⁵ Hon. Lawrence Springborg MP, *Public Hearing Transcript*, 22 August 2012, p.27

⁸²⁶ Hon. Lawrence Springborg MP, *ibid.*, p.28

- a state-wide palliative care strategy (Recommendations 32 and 33)
- population based Queensland palliative care needs assessment (Recommendation 35)
- planning and funding benchmarks (Recommendation 36)
- 24-hour palliative care information services (Recommendation 1)
- resourcing the capacity of specialist palliative care services to provide consultation services and support to GPs and other health providers, professional development and training, equipment loan services and 24-hour on-call community palliative care (Recommendations 17 and 40)
- formal partnerships between specialist palliative care services to provide consultation services to rural and regional health services and GPs (Recommendation 18)
- education for health and care providers in a palliative approach (Recommendations 22 and 23)
- public education and awareness about death, dying, advance care planning and Advance Health Directives (Recommendation 29)
- collaboration between Hospital and Health Services, residential aged care facilities, GPs and Medicare Locals to implement medication systems in residential aged care (Recommendation 12)
- promotion of increased use of videoconferencing in health services (Recommendation 26)
- a seamless Queensland Community Care information, assessment and referral service which provides case management for clients who need services from multiple providers (Recommendation 42)
- a palliative approach in the ambulance service (Recommendation 15)
- discharge planning by Hospital and Health Services (Recommendation 60) and
- case management in Queensland Community Care Services (Recommendation 61).

23.2 Improving collaboration and co-ordination

The committee believes that services need to shift to become more person-centred. This can be difficult to achieve if health, disability and community care services are not well co-ordinated. Evidence to the committee illustrated some issues that contribute to inadequate co-ordination or that are a barrier to co-ordination of services and delivery of person-centred care. Those issues included the complexity of the service system, funding arrangements, organisational 'silos', absence of a single medical and care record, inadequate discharge planning, communication barriers, and limited resources for co-ordination and case management.

23.2.1 Funding arrangements

Glenys Webby from Blue Care described funding arrangements as a barrier to co-ordination of services:

There is absolutely no doubt that the funding system we actually have at the moment is fragmented and a significant barrier to good continuum of care for people. It is also extremely frustrating for clients and families to find their way through that system. There is also no doubt that they knock on many doors before they get one that opens to meet their need, and then once they get in often they are still faced with barriers because there are walls around what we can do according to the funding.⁸²⁷

Tam Shepherd from Metro South Brisbane Medicare Local highlighted the ways that funding drives the type of services offered:

... (people) say, 'But when mum got really sick, we got told what we would be given.' When you start to dig down and look at the way the funding flows, it is exactly that. The

⁸²⁷ Glenys Webby, *Public Hearing Transcript*, 24 August 2012, p.24

*provider comes to the consumer and says, 'This is how it's going to work. This is what the package looks like. This is how it's funded.'*⁸²⁸

St Vincent's Hospital Brisbane suggested:

*... 'breaking down' of the silo mentality between departments or organizations' where the patients' best interests are not necessarily at the forefront of decisions ... the emphasis should be on the provision of care and not who provides the care.*⁸²⁹

Advocacy groups also identified the need for better integration between services. Margaret Deane of Aged and Disability Advocacy described circumstances where program restrictions mean that resources which have been purchased under one funding stream are only able to be used for a particular service, rather than to meet people's needs.

*The trouble is a lot of it is in silos. You might have had in the past a situation where HACC has a bus but that bus is only allowed to be used for HACC. There have been those restrictions, or it has been funded for another service and that four-wheel drive or whatever can only be used for that particular service.*⁸³⁰

Professor Yates noted how:

*... our models of care ... are not really very good at responding to ... complex care ... we traditionally work in our institutions, in our silos, in our hospitals and in our community sectors and the integration and the coordination between those services are very difficult.*⁸³¹

Ms Deane suggested that, particularly in rural and regional communities, collaboration between agencies funded from different sources, and pooling of resources may better meet needs.

The committee notes that funding arrangements can be a barrier to service co-ordination. The committee has recommended in Chapter 24 that the Minister for Communities, Child Safety and Disability Services monitor and report on the impact on service delivery of separation of responsibilities for community care services. This report may throw more light on the impact of funding arrangements on service co-ordination.

23.2.2 Discharge planning and co-ordination

The committee received submissions and evidence that discharge planning from hospitals is not always done, that it can ensure that patients receive the support they need, and can reduce readmission to hospital. St Vincent's Hospital's submission highlighted the consequences of poor discharge planning:

*Poor in-hospital discharge planning contributes enormously to the excessive length of stay in hospital for many patients. Discharge planning teams with the skills to access care from a number of sources in the community have been shown to reduce the length of hospital stay. However, community resources need to be available to support this. There needs to be culture of discharge planning beginning at admission to enable patients to return to home where ever possible, as soon as possible with the right support when they get home.*⁸³²

Ms Walsh, from Micah Projects, whose clients are homeless or at risk of homelessness, indicated that discharge planning is not adequate:

⁸²⁸ Tam Shepherd, *Public Hearing Transcript*, 22 August 2012, p.22

⁸²⁹ St Vincent's Hospital Brisbane, Submission no. 44, p.11

⁸³⁰ Margaret Deane, *Public Roundtable Discussion Transcript*, 28 November 2012, p.9

⁸³¹ Professor Patsy Yates, *Public Briefing Transcript*, 20 June 2012, p.2

⁸³² St Vincent's Hospital Brisbane, *ibid.*, p.7

*I think we pay lip-service to discharge planning. ... I do not think it is linked enough with the services in the community. We commonly get a Saturday phone call from a person who is being discharged who has just finished treatment ... They cannot do things for themselves. And the only option sometimes is to place them in a motel ... So we doubt the appropriate support is in place.*⁸³³

The impact of inadequate discharge planning was described by Ms Cottrell from Carers Queensland. Carers Queensland hears from carers who may be caring for a person who has been recently diagnosed and is in the early stages of needing palliative care and does not know where to get assistance. Ms Cottrell said "...we need to have some triggers when ... the medical profession becomes aware that somebody is going to need some support ...".⁸³⁴

Mr Shepherd told the committee that "there are clearly gaps in the system where people are falling off at handover points where they transition between services. There are pockets where this works and pockets where it does not ...". He said that the GP was often "lost in the equation".⁸³⁵

James Barrientos from LifeTec emphasised the capacity of assistive technology to prevent inappropriate admissions to hospital. He described LifeTec's role in discharge planning from the spinal unit at Princess Alexandra Hospital, to incorporate assistive technology in the homes of spinal injury patients, to facilitate effective discharge planning.

*... we undertake an assessment of the client and their home environment and we incorporate assistive technology into their homes, ranging from universal design for turning and reaching spaces for a person in a wheelchair to a lot of incorporated assistive technology as well—environment control units and all that sort of thing.*⁸³⁶

Information provided to the committee indicated that discharge planning is not always done well. The committee considers that discharge planning should commence at the time of admission, so that a patient can access relevant care and health services when needed. It is important that discharge information is provided, with the patient's consent, to the GP and to service providers who will provide care for the person after discharge. Queensland Health states that all hospitals and facilities have access to an electronic summary that can be provided to a patient's GP. An electronic patient discharge summary that is a:

*... legible, consistent, electronic admission summary that is delivered securely to the patient's General Practitioner (GP), allowing them to provide more timely post-discharge patient care. The summary is produced when a patient is discharged from a Queensland Health facility and is now available in all Queensland Health hospitals and facilities.*⁸³⁷

The committee does not have sufficient evidence to enable it to reach a conclusion about the reasons for inadequate discharge planning, and recommends that this be further examined.

⁸³³ Karyn Walsh, Chief Executive Officer, Micah Projects, *Public Hearing Transcript*, 24 August 2012, p.21

⁸³⁴ Debra Cottrell, Chief Executive Officer, Carers Queensland, *Public Hearing Transcript*, 24 August 2012, p.7

⁸³⁵ Tam Shepherd, *Public Hearing Transcript*, 22 August 2012, pp.21–2

⁸³⁶ James Barrientos, *Public Hearing Transcript*, 24 August 2012, pp.11-2

⁸³⁷ Queensland Health, *Patient discharge summary solution*, accessed 3 May from http://www.health.qld.gov.au/ehealth/patient_dis_sum.asp

Recommendation 60 – Discharge planning

The committee notes that inadequate discharge planning can contribute to unplanned admissions to hospital, that discharge planning should commence at admission and recommends that the Minister for Health:

- encourage Hospital and Health Services (HHS) to review and improve discharge planning in consultation with GPs, residential aged care facilities, community care and Home and Community Care service providers, and
- ensure that HHS provide timely discharge information to patients’ GPs, and where relevant other health providers, community service providers and residential aged care facilities.

23.2.3 Case management

A common theme in the information presented to the committee was the complexity of the health and community care systems, and the importance of case management as a tool to deliver care that places the person at the centre.

Kerri-Anne Dooley, Palliative Care Queensland, described an example of the effort needed to manage and co-ordinate the care for a man at home and highlighted the complexity of co-ordination. “... it took me at least 10 hours a week to coordinate this man’s care. I was visiting with a team of about seven other nurses and we had 21 shifts of personal care workers going in.”⁸³⁸

The person who is best placed for a case management role will vary according to a patient’s or client’s needs for services, and the focus of their care. Dr Julia Wootton told the committee that the “...case manager does not have to be formally appointed In different situations, a different person may be the case manager or the key worker”.⁸³⁹

Carers Queensland told the committee that the organisation is:

*... unfunded for ...a significant amount of case coordination or case management in our work. We do have some funding ... those kinds of roles are really important roles in the system. ... It is quite important ... to support people to link all of the agencies that are involved together ...*⁸⁴⁰

The committee considers that the time necessary for case management should be recognised in service planning and resourcing. It notes that the case management role may be appropriately undertaken by a GP, by a community care service provider, by a specialist palliative care service, or other health or care providers.

Recommendation 61 – Case management

The committee recommends that the Minister for Communities, Child Safety and Disability ensure that Queensland Community Care Services are resourced to provide case management for those clients who need services from multiple service providers, including health services.

⁸³⁸ Kerri-Anne Dooley, *Public Hearing Transcript*, 22 August 2012, p.8

⁸³⁹ Dr Julia Wootton, *Public Roundtable Discussion Transcript*, 14 November 2012, p.13

⁸⁴⁰ Glenys Webby, *Public Hearing Transcript*, 24 August 2012, p.24

Professor Geoff Mitchell described a model of palliative care that includes case management. The model draws on the experience of palliative care services in Spain and includes development of:

... a case management approach to the care of the people at end-of-life. The remit of these case managers will be to be a bridge between the hospital and the community care. This would help facilitate a change in approach to the patient's care within hospitals. At the same time they would ensure that care planning engages community health care professionals, particularly GPs. This would have the dual effects of ensuring that much of the care is appropriate and appropriately sited within the community and, at the same time, providing ongoing education to health care providers so that the care of the wider community is enhanced over time. The case management team would ideally include a doctor, who could be a GP, a general physician, a palliative care physician or a geriatrician. Our experience with the program that we described in your submission is that the presence of a doctor on the team opens the door to general practices to discuss cases in the first instance.⁸⁴¹

The committee considers there is merit in examining the outcomes of the pilot work led by Professor Mitchell, and encourages the Minister for Health to consider this work when outcomes are reported.

23.2.4 eHealth and technology – tools to improve collaboration and co-ordination

In Chapter 15 of this report the committee noted the importance of access to electronic clinical and care records in all care locations, so that integrated person-centred palliative care can be provided. Ideally, access to medical and care information should be possible for palliative and other medical specialists, the person's GP, nursing and other health providers and home care providers. Access should be possible from any location – hospital, hospice, medical or nurse practitioner rooms, or the person's home. Electronic systems, if well designed and implemented, have the potential to make a contribution to improved collaboration and co-ordination of care, and to support a person-centred approach.

This section describes some early success with a web-based chronic disease management system (cdmNet) which was trialed in the south-east of Melbourne for management of seven or eight chronic diseases, and which is being implemented nationally.⁸⁴²

The Victorian Minister for Health, Mr David Davis launched the Collaborative Care Cluster Australia (CCCA) in conjunction with Precedence Health Care (PHC) in August 2012. The core initiative is an online service, Chronic Disease Management-Net (cdmNet), which was developed to enable patients, their GPs and allied healthcare professionals to manage chronic disease through sharing medical histories, test results, up-dates on patients' conditions, send referrals and set appointment reminders. In the future, patients and their carers will be able to join a care conference with their GP and specialists, accessed at the press of a button from cdmNet, by video, voice or online.⁸⁴³

The cdmNet is an online 'cloud' service. It uses best practice guidelines for treatment, establishes a multidisciplinary network of health providers specific to the individual patient, and allows a health provider to take a systematic, evidence-based approach to patient management. As well as a shared patient health record, the system includes care plans and patient alerts.⁸⁴⁴

The chief executive officer of PHC, one of the partners, is Professor Michael Georgeff from the medical faculty at Monash University. Describing the value of an integrated system used by hospital,

⁸⁴¹ Professor Geoff Mitchell, *Public Hearing Transcript*, 24 August 2012, pp.39–40

⁸⁴² McDonald K, 'cdmNet to go national with Collaborative Care Plan', *Pulse+IT*, 17 August 2012, accessed 3 May 2013 from www.pulseitmagazine.com.au

⁸⁴³ Monash University, *Integrating healthcare in an internet age*, accessed 4 March 2013 from www.monash.edu.au/news/show/integrating-healthcare-in-the-digital-era

⁸⁴⁴ Georgeff M and Goldstein S, *Collaboration and Connectivity: Integrating Care in the Primary Health Care Setting*, 2013, Australian Centre for Health Research, Melbourne, p.28

GPs, allied health providers and the patient, Professor Georgeff and colleagues argue that a web-based eHealth system can enable change and improve collaboration. While the system is not a 'magic bullet' it does provide a "compelling demonstration of what can be done...".⁸⁴⁵

In their discussion of the use of an online system to integrate and co-ordinate care, Professor Georgeff and Dr Stan Goldstein argue that to meet the challenges of increasing needs for health care for chronic disease, the "existing systems designed for 'rescue' care by a single doctor need to be redesigned for managing patients ... in collaboration with an entire team of health care providers..." and that technologies should be used to enable new, value-adding processes, rather than supporting old, existing processes that add no value.⁸⁴⁶

Trials of the cdmNet found that users achieved higher quality care, GP practice productivity was enhanced, practice revenues increased and the participation of allied health and other care providers was expanded.⁸⁴⁷ Health outcomes for patients with chronic disease were improved.⁸⁴⁸

While the focus of cdmNet is on chronic disease, it illustrates the potential to transform the way that palliative care (whether for patients with chronic disease or cancer) and care in the home is delivered.

⁸⁴⁵ Georgeff and Goldstein, *ibid.*, p.31

⁸⁴⁶ Georgeff and Goldstein, *ibid.*, p.2

⁸⁴⁷ Monash University, Deakin University, Precedence Health Care, *The CDM-NET Project: Final Report, 2010*, cited in Georgeff M and Goldstein S, *ibid.*

⁸⁴⁸ Georgeff M and Goldstein S, *ibid.* p.29

Part 7 Segmentation of home and community care – State and Commonwealth responsibilities

Chapter 24. Segmentation of service system according to client age

24.1 Changes introduced in July 2012

The committee's terms of reference require it to consider the segmentation of the former Home and Community Care (HACC) service system based on age of the client, needs of the client, their carer and the providers.

As noted in Chapter 2, the former HACC program was divided in July 2012, based on clients' age, to reflect Commonwealth and state and territory responsibilities for older people and those with a disability. This segmentation of the former HACC program is an element of national health reforms.

The HACC program was, until 2012, a joint Australian and Queensland government program which provided basic community care services to eligible frail, older people, younger people with a disability and their carers. Queensland had policy and administration responsibility while the Australian Government had a broad strategic role.

Since 1 July 2012, the Australian Government has full funding, policy and operational responsibility for services delivered through the Home and Community Care (Aged Care) program for older Australians, (65 and over, or 50 and over for Aboriginal or Torres Strait Islander people) except in Victoria and Western Australia. The Australian Government program is still referred to as the Commonwealth HACC program.

At the same time, the Queensland Government became solely responsible for services for people aged under 65 (under 50 for Aboriginal or Torres Strait Islander people). The Queensland Government program is now the Queensland Community Care program, administered by the Department of Communities, Child Safety and Disability Services. Queensland Community Care Services are directed towards assisting people who have a moderate, severe or profound disability or a condition which restricts their ability to carry out activities of daily living and their unpaid carers. Community Care services are provided directly by the Department, and through non-government organisations.⁸⁴⁹

The Queensland Government began a transition away from being a direct provider of HACC services after July 2012. Queensland Health was a significant provider of HACC services; this role is being transferred to non-government organisations in locations where Queensland Health previously provided services.

24.2 Impact of age segmentation on clients and service providers

The committee invited submissions to this inquiry with a closing date in August 2012, and held most of its public hearings in November 2012, a short time after the age-based segmentation of Commonwealth HACC services and Queensland Community Care Services. In this context, stakeholders were not able to offer substantive comments on the impact of the changes. Instead, submitters highlighted potential concerns.

24.2.1 Continuity of service provision

Mr Tucker-Evans from the Council of the Ageing Queensland (COTA) told the committee that consumers were concerned that splitting HACC into two separate programs would reduce the flexibility of the previous service system. The COTA raised a number of issues, including:

⁸⁴⁹ DCCSDS, *Manual for Queensland Community Care Services*, pp.4–5

- service providers may decide to focus on only one age group, that is, people 65 and over, or people under 65. This could create transitional problems for clients who are no longer in the service provider's target age group
- uncertainty about service arrangements when a Queensland Community Care client reaches age 65, and whether they will be able to continue to receive home care services from the same service provider with whom they have an established relationship.⁸⁵⁰

While the Australian Government states that "clients will not have to change service providers because of their age",⁸⁵¹ the Queensland Community Care Services manual states that service providers who receive Commonwealth HACC funding have an "obligation to transition the service delivery to this client to outputs funded under Commonwealth HACC program ahead of accepting any new clients."⁸⁵² If the same service provider receives both Commonwealth HACC funding and Queensland Community Care funding, a client who reaches 65 would not need to change service providers.

A client of a service provider funded by Queensland Community Care Services who reaches the age of 65 may be asked to agree to a different service provider. The *Manual for Queensland Community Care Services* states that providers who do not receive Commonwealth HACC funding must "... assist the client to transition to an organisation funded to deliver Australian Government aged care services", but may only do so with the client's consent. Community Care services may continue where it is not appropriate or possible to transfer the client, e.g. where there is no Commonwealth HACC provider nearby or the client wishes to remain with their current service provider.⁸⁵³

Mr Tucker-Evans told the committee that the COTA was concerned that the split could "... create some gaps that people will fall through". The impact on vulnerable groups who may not understand what is involved, such as homeless people, those with a mental illnesses, Aboriginal and Torres Strait Islanders and people from non-English speaking backgrounds, was a particular concern. Mr Tucker-Evans suggested that both the Australian and Queensland Governments should monitor the impact of segmentation of the former HACC program into separate age-based programs.⁸⁵⁴

It is possible that segmentation of the former HACC program may have some unintended consequences, particularly in transition of Queensland Community Care clients who reach age 65 (50 if Aboriginal or Torres Strait Islander). The committee therefore recommends that the Minister for Communities, Child Safety and Disability Services monitor the impact of the segmentation of the system and report to the Parliament.

24.2.2 Administrative burden on service providers

The Queensland Aboriginal and Islander Health Council raised concerns about a potential increase in the administrative burden on service providers that receive funding to provide both Queensland Community Care Services and Commonwealth HACC services.⁸⁵⁵ Other service provider organisations also raised this as a potential issue.⁸⁵⁶

⁸⁵⁰ Mark Tucker-Evans, *Public Hearing Transcript*, 24 August 2012, pp.3–4

⁸⁵¹ DOHA, *Commonwealth HACC Program – Frequently Asked Questions*, accessed 11 March 2013 from <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-hacc-faqs.htm>

⁸⁵² DCCSDS, *ibid.*, p.22

⁸⁵³ DCCSDS, *ibid.*, pp.22–3

⁸⁵⁴ Mark Tucker-Evans, *ibid.*, 24 August 2012, pp.3–4

⁸⁵⁵ Queensland Aboriginal and Islander Health Council, Submission no. 60, p.5

⁸⁵⁶ Kincare, Submission no. 39, p.11

Recommendation 62 – Separation of HACC and Queensland Community Care

The committee recommends that the Minister for Communities, Child Safety and Disability Services monitor the impact of the separation of Commonwealth and State responsibilities for home and community care services by age in July 2012 and report to the Parliament by December 2013, particularly on:

- whether continuity of service delivery was maintained for clients who reached age 65 (or age 50 for Aboriginal or Torres Strait Islander people) between 1 July 2012 and 30 June 2013
- any increase in the administrative and reporting requirements on funded service providers in 2012–13, particularly those that receive funds from both the Queensland Community Care program and the Commonwealth HACC program.

24.3 Segmentation of services – palliative care and community care needs

Palliative Care Queensland stated that palliative care patients often did not receive HACC services. Palliative care patients have many similar needs, for example, for assistance with housework or bathing, as other clients who are frail or have a disability or chronic condition. Their submission argued that not using HACC funds for those services creates a “... drain on scarce specialist palliative care community funds” and results in more frequent, and often inappropriate, admissions to hospital or residential aged care facilities.⁸⁵⁷ A number of witnesses noted that a client receiving HACC funded services is sometimes considered to be ineligible for those services once they were classified as palliative. For example, Ms Webby said that once a client in the HACC program is assessed as within three months of death, “in theory we should not be seeing them on the HACC program”.⁸⁵⁸

24.3.1 Commonwealth funded HACC services – people 65 and over

It appears that some discretion applies to the eligibility criteria for Commonwealth funded HACC services, which service providers utilise to ensure that people receive adequate care. For example, Ms Dooley described an example where home care for a palliative patient was managed through the use of HACC services and palliative care services. She suggested there is a need to ensure

that Palliative Care Program funding ... can sit alongside (HACC services). We need to use both to keep people at home. We believe that a flexible, discretionary, person-centred model of care is what is needed to provide the quality of care that all Queenslanders need in this state.

The committee notes that the post-2012 Commonwealth HACC program does not provide “specialist palliative care services” because funding for those services is already provided through other government programs.⁸⁵⁹ The Commonwealth HACC program eligibility criteria do not exclude people with a terminal condition who receive HACC services from receiving services funded from another source.⁸⁶⁰

24.3.2 Queensland Community Care Services – people under 65

It is not clear whether, subsequent to July 2012, people with a terminal condition are considered to be eligible for services funded or delivered by Queensland Community Care Services. The Manual for Queensland Community Care Services states that while people who receive a similar service from other government funded programs are ineligible to receive Queensland Community Care,

⁸⁵⁷ PCQ, Submission no. 74, p.16

⁸⁵⁸ Glenys Webby, *Public Hearing Transcript*, 24 August 2012, p.24

⁸⁵⁹ DOHA, *Commonwealth HACC Program Manual*, 2012, Ch.1, p.4, accessed 7 May 2013 from <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-hacc-manual.htm>

⁸⁶⁰ DOHA, *ibid.*

exceptions may be made in some situations, such as when a carer is not able maintain their caring role, providing that arrangements are time limited, monitored and reviewed and do not disadvantage other members of the target population.⁸⁶¹ The committee notes that the description in the Manual could enable people with a terminal condition to receive Queensland Community Care Services, and that eligibility is not clear. The committee also notes that the evidence presented to the committee indicates there is uncertainty about eligibility of palliative care patients for Queensland Community Care Services, and suggests that the Minister for Communities, Child Safety and Disability Services clarify eligibility to provide more certainty for service providers and potential clients.

Recommendation 63 – Palliative care and Queensland Community Care

The committee recommends that the Minister for Communities, Child Safety and Disability Services clarify whether people who receive palliative care services at home are eligible to receive Queensland Community Care Services and ensure that service providers are given clear guidance on eligibility.

⁸⁶¹ DCCSDS, *ibid.*, p.12

Appendices

Appendix A – List of Submissions

Sub#	Submitter	Sub#	Submitter
001	James Toohey	039	Kincare
002	Lorna McConnachie	040	Fiona Darroch-Speedie
003	Jennie Martin	041	Regina Miller
004	STAR Community Transport	042	Name suppressed
005	Amy Lewis	043	Dietitians Associations of Australia
006	Corina Woodland	044	St Vincent's Hospital Brisbane
007	Home Instead Senior Care	045	Metro North Hospital and Health Service
008	Barbara Ashby	046	Palliative Care Nurses Australia Inc.
009	Carers Queensland Inc.	047	Occupational Therapy Australia
010	YoungCare	048	Council on the Ageing – Queensland (COTA)
011	Professor Liz Reymond	049	Deirdre Hanna
012	Dying With Dignity Queensland	050	Rev. Dr Ian Mavor OAM FACE
013	The Karuna Hospice Service Ltd.	051	Australian and New Zealand Society of Palliative Medicine
014	Heart Foundation	052	Professors Geoff Mitchell and Xavier Gomez-Batiste
015	John Russell	053	Nicole Lipp
016	Professor Janet Hardy and Decima Jones	054	National Disability Services
017	Neil Springell	055	Greater Metro South Brisbane Medicare Local Ltd
018	Micah Projects Inc.	056	Tiffany and Malcolm Heddes
019	FamilyVoice Australia	057	Julie Sutherland – Counsellor
020	Palliative Care Working Party Committee, Maryborough	058	The Royal Australian College of General Practitioners
021	Toowoomba Hospice Association Inc.	059	Ipswich Hospice Care Inc.
022	Australian Health and Hospitals Association	060	Queensland Aboriginal and Islander Health Council
023	CareConnect	061	MS Australia – Qld
024	Blue Care and UnitingCare Health	062	Professor David C. Currow
025	The Royal Australian College of Physicians	063	Queensland Clinical Senate
026	Wesley Mission Brisbane	064	Metro North Brisbane Medicare Local
027	Hopewell Hospice Services Inc.	065	Professors Patsy Yates and Ross Young
028	Tracy and Warren Taprell	066	Queensland Nurses' Union
029	Confidential	067	Australian Medical Association Queensland
030	Brett and Louise Carter	068	Leading Age Services Australia – Queensland
031	Silver Chain	069	Palliative Care Australia
032	Queensland Kids	070	Fiona Engwirda
033	Name suppressed	071	LifeTec Queensland
034	The Carers' Group	072	Anglicare Southern Queensland
035	Queensland Health	073	A/Prof Rohan Vora
036	CanTeen	074	Palliative Care Queensland
037	Cairns and Hinterland Hospital and Health Service	075	Amanda Davies
038	Family Care Medical Services	076	Department of Communities, Child Safety and Disability Services

Appendix B – Witnesses at public hearings and roundtable discussions

Witnesses at public hearings: 22 August and 24 August 2012, 4 February and 5 February 2013	Witnesses at roundtable discussions : 14 November and 28 November 2012
Dr Tina Andrews, Mount Isa Hospital	Len Airey, National Disability Services, Qld
James Barrientos, LifeTec	Veronica Corcoran, The Carers Group Bulimba
Dr Scott Blackwell, Palliative Care Australia	Margaret Deane, Aged and Disability Advocacy Inc.
Dr Will Cairns, Townsville HHS	John Haberecht, Palliative Care Nurses Australia Inc.
Jessica Casey, Mount Isa Hospital	Helen Hoare, Metro North Brisbane Medicare Local
Tracy Charlton, Karuna Hospice	Sharyn Hopkins, Queensland Nurses Union
Mrs Mary Cotterell, Mount Isa Hospital	Kris McAnelly, Australian College of Nurse Practitioners, Queensland Chapter
Debra Cottrell, Carers Queensland	Catherine Mickel, Karuna Hospice
Anna Cox, Youngcare	Prof. Liz Reymond, Metro South Palliative Care Service
Helen Davis, BlueCare	Ken Wade, Queensland Advocacy Inc
Dr Mark Deuble, AMA Queensland	Glenys Webby, Blue Care
Kerri-Anne Dooley, Palliative Care Queensland	Prof. Judy Wollin, Wesley Mission
Carol Hope, Karuna Hospice	Dr Julia Wootton, St Vincent’s Hospital Brisbane
Gary Judson, Wesley Hospital	Wallis Westbrook, Health and Community Services Workforce Council
Dr John Kastrissios, Greater Metro South Brisbane Medicare Local	
Gemma Kay, Mount Isa Hospital	
Yeshe Khadro, Karuna Hospice	
Graham Kraak, Queensland Health	
John-Paul Kristensen, Palliative Care Queensland	
Dr Yvonne Luxford, Palliative Care Australia	
Dr Martin McGahan, Private capacity	
Prof. Geoff Mitchell, The University of Queensland	
Liela Murison, Townsville Aboriginal and Islander Health Services	
Dr Marjad Page, Mount Isa Hospital	
Mona Phillips, James Cook University	
Paul Quilliam, Queensland Kids	
Gabrielle Quilliam, Queensland Kids	
Prof. Ann Rudden, Royal Australasian College of Physicians	
Tam Shepherd, Greater Metro South Brisbane Medicare Local	
The Hon. Lawrence Springborg, Minister for Health	
Joanne Tencza, BlueCare	
Mark Tucker-Evans, Council on the Ageing Queensland	
Prof. Rohan Vora, Palliative Care Queensland	
Prof. Rohan Vora, Royal Australasian College of Physicians	
Sarah Walbank, Carers Queensland	
Karyn Walsh, Micah Projects	
Glenys Webby, Blue Care	
Prof. Patsy Yates, Queensland University of Technology	
Prof. Ross Young, Queensland University of Technology	

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