Queenslanders have an historic opportunity to contribute to this inquiry which is examining Aged Care, Palliative Care and Voluntary Assisted Dying. The last of these issues, Voluntary Assisted Dying, has never previously been examined by the Queensland Parliament. This committee welcomes the views of Queenslanders on all of the issues we are examining. I encourage everyone to share their views and to treat these issues in a sensitive and respectful manner. I look forward to hearing from as many Queenslanders as possible to guide us on this journey.

Aaron Harper MP, Chair
Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee

This issues paper

This paper provides information about the inquiry into aged care, end-of-life and palliative care and voluntary assisted dying by the Queensland Parliament’s Health, Communities, Disability Services and Domestic and Family Violence Committee (the Health Committee).

Submissions to the inquiry close on 15 April 2019.

Inquiry terms of reference

On 14 November 2018, the Legislative Assembly referred to the committee an inquiry into:

- the delivery of aged care, end-of-life and palliative care in Queensland across the health and ageing service systems, and
- Queensland community and relevant health practitioners’ views on the desirability of supporting voluntary assisted dying, including provisions for it being legislated in Queensland and any necessary safeguards to protect vulnerable persons.

The Legislative Assembly further resolved that the committee should consider:

- in relation to aged care, the terms of reference and submissions made to the Australian Government’s Royal Commission into the Quality and Safety of Aged Care and, in recognising the Commission will occur in parallel, how to proactively work with the Commission to ensure an appropriate exchange of information to inform the conduct of the inquiry
- outcomes of recent reviews and work including Queensland Health’s Palliative Care Services Review, and
- the current legal framework, relevant reports and materials in other Australian states and territories and overseas jurisdictions, including the Victorian Government’s Inquiry into end-of-life choices, Voluntary Assisted Dying Act 2017 (Vic) and implementation of the associated reforms.

The committee must report its findings to the Legislative Assembly by 30 November 2019.
The following sections of the paper explain the terms of reference and the areas covered by the inquiry.

**The health service system**

The health service system in Queensland is made up of all health services provided by public and private providers in Queensland. It includes Queensland Health, the 16 hospital and health services across the state and the hospitals and clinics those services operate, private hospitals and clinics, general practitioners, specialists, nurses, pharmacists, optometrists and physiotherapists as well as allied health professions.

**The ageing service system**

The ageing service system in Queensland is made up of all aged care services provided in Queensland including in-home aged care services and residential aged care.

**Aged care**

The term ‘aged care’ covers a range of personal care and support to assist older people as they age. The Productivity Commission has described aged care as:

\[
\text{A range of services required by older persons (generally 65 years and over (or 50 years and over for Indigenous Australians)) with a reduced degree of functional capacity (physical or cognitive) and who are consequently dependent for an extended period of time on help with basic activities of daily living. Aged care is frequently provided in combination with basic medical services (such as help with wound dressing, pain management, medication, health monitoring), prevention, reablement or palliative care services.}^{1}
\]

On average around 40 per cent of older people require assistance as they age. Much of this assistance is provided by family members, friends or neighbours,\(^2\) though most older people (80 per cent) will use some form of government-funded aged care in their lifetime.\(^3\) During 2016-17, more than 240,000 older Queenslanders received some form of aged care. At 30 June 2018, there were 456 aged care facilities in Queensland that provide residential aged care: 289 (63.4 per cent) run by not-for-profit groups, 147 (32.3 per cent) run for profit and 20 (4.4 per cent) run by government.\(^4\)

Nationally, governments spent $17.4 billion in 2016-17, or $4,470 per older person on aged care services. The amount spent on aged care in Queensland was $3.23 billion, or $4,251 per older person.\(^5\)

**Aged care programs**

For older people who are able to continue living independently in their own homes with support, the Commonwealth Government provides assistance through the Commonwealth Home Support Program (CHSP) and Home Care Packages. This assistance includes nursing, personal care, cleaning, help with preparing meals, shopping, home maintenance and other tasks. At-home support is funded by the Australian Government with a contribution paid by the elderly residents.

For older people who are unable to continue living independently in their own homes, the Commonwealth Government provides funding for Residential Care. This is full-time care provided in an aged care home. Residential aged care includes accommodation, meals, laundry, personal care and nursing assistance. The costs of residential aged care are met by the Australian Government and the residents who receive the care subject to a means test.

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The **Transitional Care Program** provides short-term care for older people such as physiotherapy, occupational therapy, social work, nursing support or personal care after a hospital stay.

The **Multi-Purpose Health Services Program** supports health and aged care services in small rural and remote communities where those services would otherwise be unviable.

The **National Aboriginal and Torres Strait Islander Flexible Aged Care Program** provides funding for culturally appropriate aged care for older Aboriginal and Torres Strait Islander people close to their homes and community. These services are mainly in rural and remote areas.

**Queensland Health’s role in aged care**

Queensland Health is the approved provider under the *Aged Care Act 1997* for 63 public sector aged care services located in Queensland. Queensland Health operates 16 residential aged care facilities with a total of 1,112 places for residents, 33 multi-purpose health services, 11 transition care programs and 3 home care packages. Queensland Health also manages the Aged Care Assessment Program in Queensland on behalf of the Commonwealth Government. This program provides assessments of people’s needs for aged care services.

**Aged care reforms**

Since 2012 the Commonwealth Government has made changes to improve aged care including:

- launching the *My Aged Care* website to make information about aged care services easier to access
- allowing people to choose their aged care providers and the services they receive, and
- transferring the functions of the Australian Aged Care Quality Agency and Aged Care Complaints Commissioner to the new Aged Care Quality and Safety Commission effective from 1 January 2019.

A further 19 aged care measures were included in the *More Choices for a Longer Life Package* announced in the 2018 Federal Budget.

**Queensland’s growing and ageing population**

Demand for aged care, end-of-life and palliative care are closely linked to changes in population and life expectancy – particularly changes to the numbers of older people and people suffering from chronic illness within the population. When the number of older people increase, the prevalence of chronic diseases that are more common in older people also increases.

Queensland’s population is rapidly increasing. In December 2017, the population reached 4.9 million people which equals 20 per cent of the total population of Australia. By 2026, the population is expected to increase to 5.7 million, an increase of about 880,000 people. Of those people, one third will be aged 65 or older: an additional 300,000 older Queenslanders. By 2041, Queensland’s population is predicted to reach 7.1 million.

In addition to population growth, Queenslanders are living longer. Queenslanders and other Australians are now expected to live almost ten years longer than they were 50 years ago, with our life expectancy now the fifth highest in the OECD. The increase in longevity will result in higher numbers of Queenslanders aged 85 years and older. In 2017 87,106 people (1.7 per cent of the population) were aged 85 years and older. This number is expected to double by 2031 and further again by 2055 reaching approximately 513,000 (5.1 per cent of the population).

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Older people with disabilities

Around one in every five Queenslanders (18.3 per cent) has a disability. For older age groups, the proportion with a disability is twice the average and higher: 36.6 per cent for 65-69 years; 47.6 per cent for 70-74 years; 50.9 per cent for 75-79 years; 63.5 per cent for 80-84 years; 74.1 per cent for 85-89 years; and 85.8 per cent for people aged 90 and over.10

Aboriginal and Torres Strait islander Queenslanders

Queensland is home to a large proportion of Australia’s Aboriginal and Torres Strait Islander people. In 2016, some 27.7 per cent of Australia’s Aboriginal Torres Strait Islander population (798,365) lived in Queensland. Aboriginal and Torres Strait Islander people have a lower life expectancy (estimated at 10.6 years lower for males and 9.5 years for females) and, if required, can access aged care support from the age of 50 compared to 65 years for other Queenslanders.

The impacts of decentralisation

Queensland is the most decentralised mainland state in Australia, and this is reflected in where the state’s elderly residents live. The location of our elderly residents has important implications for the delivery of aged care services. More than a third live outside major cities with significant numbers in remote and very remote locations of the state. Of residents aged 65 or older, 424,369 (59.3 per cent) live in major cities, 177,216 (24.8 per cent) in inner regional areas, 99,138 (13.9 per cent) in outer regional areas, 8,957 (1.3 per cent) in remote areas and 5,879 (0.8 per cent) in very remote areas.

The Aged Care Royal Commission

While the committee is conducting this inquiry, a Royal Commission based in Adelaide will be examining the Quality and Safety of Aged Care across Australia.11 The committee will closely monitor the Royal Commission’s work, and will seek to maintain regular contact and work cooperatively with the Commissioners and their staff.

Issues for consideration

1. Is the aged care system meeting the current needs of older Queenslanders, including those people with special needs? Why or why not?
2. Are the current waiting times for both residential and home care places adequately meeting the needs of older Queenslanders?
3. Do the standards of residential aged care, home care and other aged care services provided in Queensland meet clients’ and the community’s expectations? Can you give examples?
4. How will demand for aged care services change in Queensland as the population increases and ages, and what changes to the aged care system will be needed to meet future demands for aged care?
5. Are there enough residential aged care places (beds) available in aged care facilities, in areas and at the levels of care that are required?
6. Are adequate numbers of home care packages available in areas at the levels required?
7. Are there sufficient staff in the aged care sector to meet current and future workloads?
8. Is the mix of staff appropriate for different settings within the aged care sector?


11 Information about the Australian Government’s Royal Commission into the Quality and Safety of Aged Care, including terms of reference, is available at https://agedcare.royalcommission.gov.au.
9. Do aged care staff receive training that is appropriate and adequate to prepare them for the work?

10. What are the costs to the public health system of caring for elderly people in hospitals whilst they are waiting for residential aged care places to become available?

11. Are suitable health care services being provided within residential aged care settings and/or aged care providers?

12. Is the current aged care system making an appropriate contribution to the health of older Queenslanders, within the context of the broader health system in Queensland?

13. How can the delivery of aged care services in Queensland be improved?

14. Are there alternative models for the delivery of aged care services that should be considered for Queensland?

15. How will the model of aged care develop with evolving technology and medical practices?

16. What are the key priorities for the future?

### End-of-life and palliative care

**Palliative care** can be defined as “person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life”. It is care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness.12

Palliative care provides vital support for people who have serious illnesses of all ages, including children, and their families.

**End-of-life care** is care provided to a patient with a life-limiting illness during the last stages of life. The needs of patients and their carers are greater at this time.

Palliative and end-of-life care can be provided in a person’s home, in a hospital or in a clinic.

The Commonwealth and Queensland Governments share responsibility for palliative and end-of-life care in Queensland, including for funding.

**Queensland Health’s review of palliative care services**

When the committee commenced its inquiry, Queensland Health was in the final stages of a review of the state’s palliative care services. The committee has asked for a report from this review to use for the inquiry.

### Issues for consideration

17. What are the palliative care services offered in Queensland?

18. Are palliative care and end-of-life care services meeting the current needs of Queenslanders? Why or why not?

19. Do the standards of palliative care and end-of-life care provided in Queensland meet clients’ and the community’s expectations?

20. How will demand for palliative and end-of-life services change in Queensland as the population increases and ages, and what changes to the delivery of these services will be needed to meet future demands?

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21. How can the delivery of palliative care and end-of-life care services in Queensland be improved?

22. What are the particular challenges of delivering palliative and end of life care in regional, rural and remote Queensland?

23. What are the particular challenges of delivering palliative and end of life care for Aboriginal and Torres Strait Islander communities?

24. What are the key priorities for the future?

**Voluntary assisted dying**

For the inquiry, the committee is also reporting on the views of the Queensland community and relevant health practitioners on the desirability of supporting voluntary assisted dying (VAD). This includes views on the desirability of supporting VAD, including provisions for it being legislated in Queensland, and any safeguards that may be needed to protect vulnerable persons.

The terms of reference also state that the committee should consider the current legal framework, relevant reports and materials in other Australian states and territories and overseas jurisdictions, including the Victorian Government’s Inquiry into end-of-life choices, *Voluntary Assisted Dying Act 2017* (Vic) and implementation of the associated reforms.

The committee is examining the legal frameworks in other countries where forms of VAD have been implemented as well as in Victoria where a VAD scheme will become legal this year. The committee is also monitoring developments in Western Australia and New Zealand where VAD schemes are being considered.

**Variation in definitions**

The term ‘voluntary assisted dying’ or VAD, while often used, does not have a universally-accepted definition and can mean different things to different people. It is sometimes used interchangeably with terms such as euthanasia, which is also widely used and lacks a universal definition.

The quote below from the Australian Human Rights Commission discussed this point regarding the definition of euthanasia, which can just as easily be applied to VAD, when it noted that euthanasia is:

> Often incorrectly characterised as one particular kind of practice. However, it is more accurately understood as an umbrella term which covers an array of practices that can be described as different forms of euthanasia.\(^{13}\)

This is a point also highlighted in a response to an article in the British Medical Journal:

> There is no stable consensus as to the meaning of “assisted dying”.\(^{14}\)

**Characteristics of a potential voluntary assisted dying scheme**

Based on other VAD schemes, the features of a potential VAD scheme for Queensland could include:

- a person must want to end their life for a reason they consider to be valid
- a person must provide their consent to have their life ended
- a person must have capacity to make the decision to have their life ended, and
- a third party, such as a medical practitioner, may assist in ending that person’s life.

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\(^{14}\) D Jones, ‘Getting our definitions right in the debate over assisted suicide and euthanasia’ *The British Medical Journal*, 19 August 2015 – response to the article: Assisted dying: law and practice around the world, *The British Medical Journal*, 20 August 2015. (Please note, a journal account is needed for full access to the article).
Voluntary assisted dying schemes overseas

A number of jurisdictions in Europe and North America have schemes that could broadly be defined as VAD. Table 1 summarises some of the key elements of VAD schemes in those jurisdictions.

Community support for voluntary assisted dying in Queensland

For the inquiry, the Legislative Assembly has tasked the committee with gauging community and health practitioners’ views on the desirability of VAD in Queensland.

Features of any potential voluntary assisted dying scheme

VAD schemes overseas have a range of requirements in place to ensure only people who were intended to access them are able to, while having safeguards to reduce the risk of people being coerced into participating.

Table 1 – Overview of selected overseas voluntary assisted dying schemes

<table>
<thead>
<tr>
<th>Country/ year commenced/ legislation</th>
<th>Key features</th>
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</table>
| Belgium 2002 Act on Euthanasia 2002 | - Patient must be suffering intractable and unbearable pain  
- Patient must freely express their wish to die  
- Doctors can help patients end their lives  
- Under 18s can access the scheme, if they are deemed competent |
| Luxembourg 2009 Law of 16 March on euthanasia and assisted suicide | For euthanasia and assisted suicide:  
- Patient’s condition must be incurable, with no chance of improvement and they must suffer unbearable mental or physical suffering  
- Patient must make request to die voluntarily and repeatedly  
For euthanasia:  
- Patient’s life ended by a physician  
For assisted suicide:  
- Patient ends their own life |
| The Netherlands Evolved from 1973 to 2002  
Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002 | - Voluntary euthanasia and assisted suicide are criminal offences, despite the Act  
- Physicians avoid prosecution if they report their actions in assisting a patient’s death to a Regional Euthanasia Review Committee and if they meet ‘due care’ criteria  
- Patient does not need to be terminally ill  
- Patients aged 16 – 18 can access voluntary euthanasia if they have a reasonable understanding of their own interests and parents or guardians have been involved in the decision-making process  
- Patients aged 12 – 15 can access voluntary euthanasia if the conditions above apply and their parents or guardians consent to the decision  
- Patient does not need to be competent when voluntary euthanasia is carried out if a valid advance directive was completed when they were competent |

Most of the information in this table was sourced from the Western Australia Joint Select Committee on End of Life Choices – Western Australia, Parliament, Report 1, MY LIFE, MY CHOICE The Report of the Joint Select Committee on End of Life Choices, August 2018, pp 152 – 158.

Court cases in 1973 and 1984 gave some scope for a doctor to end a patient’s life. The 2002 Act legislated for a scheme.

To meet the due care criteria, the physician must:  
1. be satisfied that the patient has made a voluntary and carefully considered request;  
2. be satisfied that the patient’s suffering was unbearable, and that there was no prospect of improvement;  
3. have informed the patient of his situation and his prospects;  
4. have concluded, together with the patient, that there is no reasonable alternative in light of the patient’s situation;  
5. have consulted at least one other independent physician who must have seen the patient and given a written opinion on the due care criteria at 1 – 4 above; and  
6. have terminated the patient’s life or provided assistance with suicide with due medical care and attention.

<table>
<thead>
<tr>
<th>Country/ year commenced/ legislation</th>
<th>Key features</th>
</tr>
</thead>
</table>
| Switzerland 1942                   | - A person can participate in an assisted suicide if they do so free from unselfish motives  
|                                    | - A person participating in a suicide must demonstrate they have not had self-serving ends¹⁹  
|                                    | - No eligibility criteria or safeguards  
|                                    | - Available to citizens and non-citizens  
|                                    | - No piece of legislation provides for VAD – the scheme is based on provisions in the Criminal Code that have operated since 1942 |
| Canada 2016 Province of Quebec     | - Called ‘physician assisted dying’ and legal for all persons over 18 years of age with a terminal illness that has progressed to the point where natural death is ‘reasonably foreseeable’  
|                                    | - Only people who are entitled to claim Canadian health insurance (ie Canadian citizens) are eligible  
|                                    | - Legalised in 2016 after the Supreme Court struck down a ban on medically assisted suicide, and both houses of parliament passed a government Bill (C-14) to amend the Criminal Code and other Acts to legalise assisted dying for those with terminal illness for whom death is reasonably foreseeable  
|                                    | - The Quebec provincial parliament in 2014 passed a Bill (Bill 52) to legalise medical aid in dying for mentally competent patients who meet a strict set of criteria |
| USA Washington State 2009         | - The Washington Death with Dignity Act, Initiative 1000 codified as RCW 70.245, passed on November 4, 2008 and commenced on March 5, 2009  
| Death with Dignity Act            | - This act allows terminally ill adults seeking to end their life to request lethal doses of medication from medical and osteopathic physicians  
| Oregon 1997 Death with Dignity Act| - Patients must be Washington residents who have less than six months to live. See FAQs  
|                                    | - The Oregon Death with Dignity Act allows terminally ill citizens of Oregon who meet specific qualifications to end their lives through the voluntary self-administration of a lethal dose of medications, expressly prescribed by a physician for that purpose |

**Issues for consideration**

25. Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?

26. How should VAD be defined in Queensland? What should the definition include or exclude?

27. If you are a health practitioner, what are your views on having a scheme in Queensland to allow VAD?

28. If there is to be a VAD scheme, what features should it have?

29. Are there aspects of VAD schemes in other jurisdictions that should, or should not, form part of any potential VAD scheme for Queensland, and why?

30. Who should be eligible to access VAD and who should be excluded?

31. Should the scheme be limited to those aged 18 and over? If so, why? If not, why not?

32. Under what circumstances should a person be eligible to access VAD? Could it be for example, but not limited to, the diagnosis of a terminal illness, pain and suffering that a person considers unbearable or another reason?

33. What features should be included in a process to allow a person to legally access VAD?

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¹⁹ According to the Swiss Ministry of Justice, self-serving ends would cover assisting a death ‘to satisfy material or emotional needs ... the possibility of eliminating some major problem for the family, or other motives such as gaining an inheritance, relieving himself of the burden of supporting the individual ... or eliminating a person he hated.’ From: The Royal Society of Canada, *End of life Decision Making*, November 2011, p 81.
34. What safeguards would be required to protect vulnerable people from being coerced into accessing such a scheme, and why?

35. Should people be provided access to counselling services if they are considering VAD? If so, should such counselling be compulsory? Why?

36. How could a VAD scheme be designed to minimise the suffering and distress of a person and their loved ones?

37. Should medical practitioners be allowed to hold a conscientious objection against VAD? If so, why? If not, why not?

38. If practitioners hold a conscientious objection to VAD, should they be legally required to refer a patient to a practitioner that they know does not hold a conscientious objection or to a service provider that offer such a service? If so, why? If not, why not?

Other issues submissions could cover
As with all inquiries, the committee is open to people expressing their views on any aspect of the inquiry they consider appropriate, provided submissions include basic contact information.20

How to contribute to the inquiry
The committee welcomes public participation in its work.

Keep informed about the inquiry
You can subscribe to receive regular email updates about the committee and the inquiry or register as a stakeholder. Check the inquiry webpage for the details here.

You can also follow the work of the committee via the Parliament of Queensland’s social media accounts:

Provide a submission
The committee invites submissions on the issues identified for consideration in this issues paper, and any other issues relevant to the terms of reference. General guidelines on making submissions are available from the committee’s webpage here.

Written submissions can be posted to:
Committee Secretary
Health Committee
PARLIAMENT HOUSE QLD 4000

or faxed to: 07 3553 6699

or emailed to: careinquiry@parliament.qld.gov.au

If you have difficulties sending your submission, please call the secretariat staff ph (07) 3553 6626 or 1800 504 022.

Auto-generated or copied submissions
The committee discourages interest groups from providing prepared text for their members to lodge by email or fax as their own individual submissions to the inquiry. Receiving multiple copies of the same

20 Which should be: the author’s name; if the submission is made on behalf of an organisation, the level of approval (eg a local branch, executive committee or national organisation); a postal address; email address (if available); and a daytime telephone number.
submission, or substantially the same submission, adds no value to the inquiry. The committee will not treat these copied submissions as individual submissions.

Submission form
The committee has produced a form to assist people who do not use email to provide a submission to the inquiry by post or fax. The form is available from the inquiry webpage [here](#), or by calling the secretariat staff.

Confidential submissions and disclosures to the committee
Given the nature of the issues covered by this inquiry, the committee anticipates that people may wish to share information in their submissions and other evidence for the inquiry that is highly personal, or which may involve criminal behaviour. If you believe your submission, or parts of your submission, should be treated confidentially by the committee and not published, please make this clear in your submission and include a brief explanation for the committee to consider.

Submission closing date
The closing date for lodging submissions to the inquiry is **Monday 15 April 2019**.

Attend the committee’s public hearings
The committee will publish the locations, dates and times for its public hearings for the inquiry on the inquiry website [here](#). These are public meetings of the committee and all stakeholders and interested parties are welcome to attend as observers. If you would be interested in giving evidence at a public hearing, please note this in your submission.

Committee Members
Aaron Harper MP  
(Chair)  
Member for Thuringowa (ALP)

Mark McArdle MP  
(Deputy Chair)  
Member for Caloundra (LNP)

Michael Berkman MP  
Member for Maiwar (GRN)

Marty Hunt MP  
Member for Nicklin (LNP)

Barry O’Rourke MP  
Member for Rockhampton (ALP)

Joan Pease MP  
Member for Lytton (ALP)

Contacting the committee
Questions about the inquiry should be directed to the committee’s secretariat:
Phone:  07 3553 6632 or Freecall: 1800 504 022
Email:  [careinquiry@parliament.qld.gov.au](mailto:careinquiry@parliament.qld.gov.au)
Inquiry into aged care, end-of-life and palliative care, and voluntary assisted dying

The Queensland Parliament’s Health Committee is considering how aged care, end-of-life and palliative care are delivered for Queenslanders. The committee is also considering, and seeking views on, whether voluntary assisted dying should be allowed in Queensland.

We want all Queenslanders to have their say on these important issues. See the committee’s issues paper for more information. Let us know your views below.

The committee is taking comments for the inquiry until 15 April 2019.

Your details:

Mr/Ms/Mrs/Dr:

Day time phone number: (    )

Email address:

Address: Postcode:

What would you like to tell the committee?

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Publication of your comments:
The committee may publish your comments as a submission. For comments provided by individuals, the committee will first remove personal contact details such as phone numbers, street addresses and email addresses.
I agree with the publication of my comments as a submission  ☐ Yes  ☐ No

Request for the comments to be treated confidentially by the committee:
If you have provided personal information or other information you would like to be kept confidential by the committee and not published, please explain briefly your reasons why:

Are you providing comments on behalf of others or an organisation?  ☐ Yes  ☐ No

If yes, please tell us the name of the person or persons or organisation:____________________________________
Their daytime phone number: :____________________________________________________________________
What is your relationship with that person or persons, or your role in the organisation?_______________________

I am authorised by …………………………………………………… to provide these comments on their behalf.

Signature:.................................................................................. Date: .................................................................

Need Help?
If you have any questions about the inquiry or making a submission, please call the committee secretariat:

07 3553 6626 or 1800 504 022 Free call