Submission to the Health and Environment Committee,

Queensland Parliament

Response to the Voluntary Assisted Dying Bill 2021

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Dear Secretariat and Committee members,

RE: Health and Environment Committee Inquiry into Voluntary Assisted Dying Bill 2021

Thank you for the opportunity to provide a submission to the Committee for the inquiry into Voluntary Assisted Dying Bill 2021.

Introduction

Health Consumers Queensland has heard throughout our statewide consultation with consumers that there is strong support for voluntary assisted dying with sufficient safeguards and that this enables the individual choice to decide when and how they die.

Choice and dignity are highlighted and must be ensured to meet the needs and expectations of the community.

Throughout this process of the Law Reform Commission Inquiry and Bill preparation we have engaged deeply with consumers across the state. We have hosted several series of Kitchen Table Discussions. These were hosted and facilitated by consumers and carers within their own community. This is a methodology that we have developed to enable the voices of diverse and often hard to reach consumers in a safe and meaningful way. We have heard rich engagement with over 500 consumers throughout this process. Our engagement around End of-Life care and consumer wishes dates back many years including our 2015 partnership with the Queensland Clinical Senate on high benefit and high quality care at End of Life.

This submission is also based on our Board's input and consumer-focused principles of person-centred, integrated health care:

- Accessibility - safe, affordable and high-quality services, treatments, preventative care and health promotion activities.
- Respect - healthcare that meets consumers' unique needs, preferences and values
- Choice – a responsive health system which ensures consumer choices in prevention, treatment and management options
- Participation - patient involvement in health policy to ensure that policies are designed with the patient at the centre.

Consumers focus on dignity of choice to die in the manner that they wish. They see that Voluntary Assisted Dying (VAD) (or as commonly termed Euthanasia) is *“directly related to dignity, care and professionalism.”*

Access to excellent palliative care is also highly important at end of life for consumers and not an either-or situation/decision.

Access to information regarding end-of-life choices should be detailed and early to allow consideration so that consumers can make prepare their decisions.

We commend the focus on access to information about VAD and the support of care navigators.

However, this process needs to be supported by broader communication and change management. As we have heard from consumers over many years, that issues arise due to cultural aspects that as a society we do not talk about death and dying and that clinicians are not comfortable and supported to have these discussions to support choices with consumers and their families. Consumers shared about their focus on educating themselves about high quality care at end of life to be aware of what is available and that there needs to be support for health literacy and education in this process. The changes to community conversations, clinical and consumer health literacy and comfort in discussion about end-of-life choices all needs to be part of the work of change to make this Bill successfully implemented.

Additionally, we commend the focus on access to VAD not be impeded by institutional objections. In monitoring of data, we request that issues be monitored to ensure that safeguards as set out in the Bill are sufficient.

Recommendations

Recommendation: Timeliness and timebound actions are important especially in relation to equity and access to care

We recommend that the timeframes are monitored from request of the patient to appointment of a medical practitioner who will accept conducting the first assessment and the conduct of subsequent assessments. That reporting of data be in place to direct and determine issues of access and equity regarding the implementation and be publicly reported on a 6-monthly basis for at least the first two years and reviewed thereafter.

Recommendation: Supported decision making for consumers with a cognitive disability and/or impaired decision making capacity

Consumers can have a cognitive disability, and still have decision making capacity. This can include people with an acquired brain injury, psychosocial disability, neurological disability, etc. These consumers need to be given information about their options at the end of life in an accessible way that works for them, to enable them to make informed decisions. This may include simplified information, extra information or detail, time to consider their options and discuss if they wish with caregivers or family.

For consumers with impaired decision making capacity or those with significant impacts on their ability to make decisions (whose have family or substitute decision makers deciding their care), they still deserve a process that maximises their ability to be part of decision making around their care options at end of life.

We recommend specific engagement and attention be given to this issue during the finalisation of the bill and implementation if it passes with key NGOs such as QDN and QAI.

Recommendation: Aboriginal and Torres Strait Islander organisations and communities

Need to engage more strongly with Aboriginal and Torres Strait Islander organisations and communities to ensure the legislation and implementation meets their needs and concerns.

Recommendation: **Bereavement care for all**

We support the Palliative Care Queensland recommendation that Clause 5d be amended "*Every person and their families should have access to bereavement care from diagnosis of a life-limiting illness to a minimum of 12 months after the death***".**

Recommendation: Inclusion of social workers

That S85 be amended to include social workers and that their activity be defined

Recommendation: **Monitoring and Reporting of the Bill effectiveness**

To ensure that the Bill is implemented in a manner that ensures safety, quality, access and equity for patients, families and communities we recommend that there is monitoring and public reporting on the Inform My Care website. As stated, that this includes timeframes, institutional access, patient and family reported experiences and access to nurse navigational services.

Listening to consumers and carers – what we've heard

Over the last two years we have heard the voices of over 500 Queenslanders who are very clear on what matters to them in relation to ageing, end-of-life care and dying. As much as there were many positive stories shared, the greater proportion came to be listened too, and share their challenges with care received by their loved ones. The participants have welcomed these opportunities to share their desire to see systemic change concerning ageing, end-of-life care and dying.

In the first round of consultation in 2019 Health Consumers Queensland along with COTA Queensland, Palliative Care Queensland and Carers Queensland partnered with Clinical Excellence Queensland, Queensland Health to undertake consultation with consumers and carers on "*What matters to them in relation to ageing, end-of-life care and dying*".

In the second round of submissions to the QLRC in 2020 our consultation process involved:
20 kitchen table discussions held across Queensland over a two-week period in March 2019 with 183 community members. The Kitchen Table Discussions were hosted and facilitated by consumers and carers within their own community. Each host was provided with five key questions for their discussions. This is a methodology that we have developed to enable the voices of diverse and often hard to reach consumers in a safe and meaningful way.

Sixteen focus groups were held across the state with consumers and carers in April, May, June and July 2019. Twelve were facilitated in rural, remote and regional locations and 4 in Brisbane with one session specifically for People who Identify as Forgotten Australians. Thirteen key themes emerged from the consultation with a consistency of feedback across the 20 sessions:

1. Staying at home (care in the home)
2. Access to quality and timely care and support
3. Better Information and knowledge, better navigation and choice
4. Voluntary Assisted Dying – Dignity and Choice
5. Care Choice (choice around what I need/individualized)
6. Informal Support System (family carers, volunteers, community)
7. Workforce (paid support workers/health professionals)
8. Palliative Care
9. Emotional Support, Burden and Risk
10. Financial Support, Burden and Risk
11. Communication
12. Transport
13. Housing

Our latest consultation conducted in April/May 2021 is detailed below. We held 19 kitchen table discussion with 131 consumers and carers on High-benefit care at the End-of-Life on behalf of the Healthcare Improvement Unit, Clinical Excellence Queensland. The Kitchen Table Discussions were hosted and facilitated by consumers and carers within their own community, state wide across 13 towns and cities.

Sometimes, the treatment and care provided to those who have been diagnosed with a life limiting condition (including advanced disease and frailty) does not align with the wishes and values of those who receive it. This consultation sought to understand what high and low value care means to consumers, in addition to better understanding how consumers can be empowered to participate in decisions about treatment and care that is right for them. Understanding the needs of the consumer, right from the point of diagnosis of a life limiting condition, is essential for developing strategies that ensure the delivery of high benefit, patient centred care at end of life.

- **94.07% of participants said they would want to know if they were to be diagnosed with a life limiting condition.**

- Learning more about their illness from their family GP or treating doctor is participant's preference with a follow up appointment with a specialist/health professional or condition-specific clinic.
- Receiving the news face to face is a priority as is having someone with them when receiving a diagnosis.
- Receiving their diagnosis face-to-face is important but needs to be supported by written information that is in plain language and easy to understand. Checklists are considered helpful.
- **Knowing all the choices and available treatment and care options and having questions answered honestly is a priority. Along with being respected, treated with dignity and having a clear understanding of what is happening with their treatment and having the choice to continue or stop.**
- **A follow up appointment with their GP, specialist or care team will assist in making informed choices and treatment decisions.** This also allows for family members to attend and assist with taking in the information and providing support with asking questions.
- It's important for families and care givers to also be heard and involved in decision making.
- **The majority of participants said they would want to know if diagnosed with a life-limiting illness and the treatment options provided have not been proven to work well or may make them worse.**
- To assist those diagnosed express what their needs are would include **honest communication, empathy, and trust in their care team and having instant access to information and to other health professionals who are experts in their condition is a necessity.**
- Having additional time at their appointments to ask questions.

Considerations about communication

We note that many consumers we have engaged with use the term "euthanasia" rather than Voluntary Assisted Dying (VAD). This should be considered in the broader communication with the community. Here in our direct quotes from consumers, euthanasia is frequently stated.

Access to Information about Voluntary Assisted Dying

We heard that very early on the patient and family should be given information regarding what their end-of-life choices are (e.g., decisions relating to resuscitation etc.). This should be quite a detailed document that sets out people wishes. Statement from a Kitchen Table consumer:

> *Even if euthanasia [VAD] is not legal in that State, the patient should still be able to state if they want to be euthanised or not. Who knows a change in legislation may enable this for some people down the track? Maybe in this document, the patient could describe what they did NOT want to be like at end-of-life.*

People want information face to face and they would like to know that their clinician at the end of life will support them with their choices. If clinicians have a conscientious objection to VAD then they make this transparent to their patient and family to support that patients want to make end of life choices early.

The Bill does not currently set out the timing of when discussions are held with patients however there is a focus on it being linked to the time of request rather than as part of high-quality care of the clinician with the patient.

Participants said you need to be fully informed and provided with all options to make an informed choice, but you should not be pressured to make decisions immediately, instead you should have time to consider the options outside of the appointment. Having a comprehensive explanation on the diagnosis is important as is being kept up to date on the effectiveness of the agreed treatment and care plan. As one participant said, **“***Throughout the whole process – it is my life!”.*

Access to Voluntary Assisted Dying

In our recent engagement on behalf of Clinical Excellence Queensland we asked about High Benefit Care at the end of life.

Consumers want the option of euthanasia/VAD. For some, High benefit care at the end of life means:

- Being made completely comfortable and pain free, the choice to be Euthanised.
- To do whatever is possible to look after the person needing care.
- To have excellent palliative care.
- The opportunity for Euthanasia.
- Best possible care.

They see that the option of VAD/Euthanasia should be in place and that it would “That would result in a high level of health benefit from a small investment of resources!”

We heard deeply moving stories from consumers throughout this consultation. An example is shared here with permission:

> *Having the right to choose for my end-of-life meaning voluntary euthanasia and not having to travel to another state to access it, I am facing going through to Stage 4 of metastatic melanoma and ceasing all treatments due to it not working. So now I live with my wife in Qld. But I am originally from Victoria and still own land there and have family down there. So, when it gets to the end of my life, and I do not want to be a burden anymore on my wife. I am now facing the choice to potentially have to move to Victoria to be with my family for a period of time so I can access my right to choose euthanasia there. This potentially means my wife may have to stay in Qld as she is our sole income earner now, so due to it not being legal in Qld I may have to be apart from my wife towards the end of my life for an extended period. Which is not right and not fair on her.*

The importance of timing and timeliness

The Bill sets out a number of timings which recognises the importance of time in relation to VAD process and decision making. The timing currently helps the process where everything is running smoothly. It does not address issues where intentional or unintentional delays could be introduced such as by conscientious objectors where services are referred to other services are not successful. Highlighting that there is a higher risk of this situation arising in rural and remote areas where there is reduced choice of practitioners. We note issues that have arisen in other states where there are challenges in accessing the law which relate to time and timeliness.

We recommend that the timeframes are monitored from request of the patient to appointment of a medical practitioner who will accept conducting the first assessment and the conduct of subsequent assessments. That that be in place to direct and determine issues of access and equity regarding the implementation.

Care Navigator Role

We commend that a Care Navigator role is proposed in the Bill. Before it is established, we would like to see consumers involved in what the Care Navigator role will be, where the roles will be provided/located and who will manage the roles i.e., HHSs, what training they will undertake, and ongoing assessment and review of the Care Navigator role in terms of demand and capacity and how this role ensures the desired access and equity.

In our consultation, health consumers recognised the roles beyond a medical practitioner. Navigation and service co-ordination are issues facing patients and families. There were requests for the introduction of a nurse navigator role to support patients and families to navigate end-of-life and palliative care access, information, choices and support services. Thursday Island consumers talked about the lack of indigenous case management and need for an advocate (Indigenous Liaison Officer) to support them and their family member in hospital.

Choice of care and individualised care were another consistent message throughout the consultations. Consumers clearly indicated they want choice when it comes to care and end-of-life options, to know what choices are available to them and where care is delivered.

It is hence fundamental that this choice and need is not blocked and impaired by the consumers' access to a suitably qualified medical practitioner who is both willing and able to act on the wishes of the consumer. Given that the consumer may be suffering significant pain and distress this referral and access should be timely and feasible for the consumer to access.

Establishing a navigator role similar to nurse navigators with Queensland Health provides a level of support to patients and their families that may not currently be available. This would support consumers to understand the decisions they need to make, the choices and options available to them towards the end stage of life. This would reduce the burden on both the patient and their family in making their choices, also helping them navigate the challenging paperwork requirements. It would also alleviate the reliance on a single point of contact with the health practitioner should they conscientiously object.

Advocacy is another area of support sought by those who have no one to advocate for them including those who identify as Forgotten Australians. Others spoke of the need for an advocate to be an impartial or non- biased voice as part of their end-of-life care decisions.

Another reason for an advocate or navigator-type support involved people remaining in their home with support services. Some people say they have too many different services coming into their home which is causing confusion for them.

Health Consumers Queensland supports that there is patient safety and care is paramount. We support that there are minimum qualification and experience requirements. The needs across the state should be assessed to ensure that both safety and access as ensured for all Queenslanders with this requirement in place.

Conscientious Objection

We note that in the Bill, under the heading of Conscientious Objection, Part 6 Division 1 S84 and S85, refers to registered health practitioners, and specifically in Cl 85 to "***Speech pathologist with conscientious objection***".

They are not required to be registered with the Australian Health Practitioner Registration Agency (AHPRA) as is the case for **social workers**. We believe that it is more likely that social workers would be required to be involved in the VAD process from providing initial information if requested, to other relevant actions with patients and their loved ones. Therefore, S85 should also include social workers and provide a definition of that activity in line with the definition outlined in S85 (5).

First Nations

Broach community engagement is essential for the success of Voluntary Assisted Dying in Queensland. We are not clear about what engagement has been undertaken to date with Aboriginal and Torres Strait Islander communities. We recommend the need to engage strongly with First Nations organisations and communities to ensure this Bill meets their needs and concerns.

Bereavement Care

Bereavement is the state of loss, and grief is the response that follows this change or loss. Grief is the process of coming to terms with change and loss, it is profoundly personal. Grief is a challenging experience for persons, families and their communities. Palliative Care Queensland outlines that 2019, there were 32,473 deaths recorded in Queensland. If, on average, each death impacts 6-8 close family and friends, this may suggest at least 250,000 close family and friends are grieving for a significant other each year in Queensland. As a result, bereavement care is a substantial health concern.

They cite that:

In 2020 PCQ conducted a series of consultations in relation to Bereavement Care in Queensland including Consumer-Hosted discussions through Health Consumers Queensland (Kitchen Table Discussions). These identified a range of consumer experiences and needs in Queensland. This included service-based and practical needs such as bereavement follow-up from qualified services, accommodation for families, access to low-cost funerals and to meaningful and culturally appropriate funerals, complementary therapies, increased awareness and information about grief and loss for community members. A number of participants identified the need for services and supports to extend to rural and regional areas.

Some participants had traumatic experiences due to not being allowed to visit family members in hospital during the pandemic. Lockdowns and border closures contributed to this situation. For some, this blocked the intimacy of families grieving together and supporting one another during bereavement.

Reduced attendance at funerals also caused trauma, including the difficult choice of who would be invited to attend. Funerals are an important ritual for all and an especially sacred one for Aboriginal and Torres Strait Islander people, who have large families and often funerals are attended by up to or more than 500 people. With the impact of the pandemic likely to continue for several years, the COVID access issues with bereavement could continue to create a bigger impact under Voluntary Assisted Dying.

*"As soon as a person enters palliative care there should be a service dedicated to supporting the patient and their families during and after their death for up to 12 months. If they are getting the right service, it will help them move through that grief process a lot better than not having the service" (*Consumer participant).

We support the PCQ recommendation that ***Clause 5 (d) be amended to include the words "Every person and their families should have access to bereavement care from diagnosis of a life-limiting illness to a minimum of 12 months after the death"***

Needs of Culturally and Linguistically Diverse Communities

We commend the focus on the need for specific supports and use of interpreters for culturally and linguistically diverse people. We heard in our engagements that having care workers who were of their culture or who spoke their language was important. They asked to be spoken to in their language. Provide more culturally appropriate care with a focus on ethnically cultural in-home care with broader definitions around care activities to ensure cultural needs are being met.

The need for explanation of care etc. to be in non-technical language is part of quality care delivery however for many it is an issue. Information that is currently provided on care packages and options is deemed to be ‘too complicated when already overwhelmed’, as is the documentation for Advanced Health Directives. More consumer-friendly forms are required and more consultation with consumers to develop the forms and promotion of Advanced Health Directives.

Principles of Voluntary Assisted Dying

We support the principles as a key element that are used for complex and ethical decisions where individual situations specifically require that decision making remain within the intent of the ethical, social, emotional and psychological well-being for the individual and their family and personal connections. This also helps to translate to the community how decisions about voluntary assisted dying will be made with them. It helps to act as a bridge to translate communications between expert health professionals and the community both generally regarding the legislation introduction as well as in its specific implementation.

The Australian Commission on Safety and Quality in Healthcare is the custodian of the Australian Charter of Healthcare Rights, which sets out the principles for access to and safety to health services for all Australians. Health Consumers Queensland has just launched a Charter for Digital Health for Consumers (co-designed by consumers and funded by Queensland Health). A Charter outlining principles for voluntary assisted dying would clarify and assist in the understanding and trust building for such legislation to the public.

Three aspects where particularly highlighted in discussions relation to VAD:

- Choice to decide timing of death
- Choice of VAD due to other options of care not being satisfactory (i.e., palliative care and nursing homes)
- Current health system focus on “keeping people alive”

In addition, in that choice, they want dignity to be maintained. For others it was important to bring their family member home to die and not have them end their life in hospitals or aged care facilities. Communication between service providers and patients/families was highlighted as an issue.
For those who are vulnerable and culturally and linguistically diverse having access to appropriate communication methods is of prime importance as is access to interpreters or staff who speak their language.

People want others to listen, to act on and respect their wishes. They want their decisions and choices to be honoured by their family, as well as health professionals.

Conclusion

Health Consumers Queensland has heard from consumers across Queensland that there is st5rong support for voluntary assisted dying with sufficient safeguards and that this enables the individual choice to decide when and how they die.

Choice and dignity are highlighted and must be ensured to meet the needs and expectations of the community.

Health Consumers Queensland is available to engage further on our position on the Voluntary Assisted Dying Bill.

About us

Health Consumers Queensland is the peak organisation representing the interests of health consumers and carers in the state.   Health Consumers Queensland is a not-for-profit organisation and a registered health promotion charity, and we believe in improving health outcomes for people in Queensland.

Consumers are people who use, or are potential users, of health services including their family and careers. Consumers may participate as individuals, groups, organizations of consumers, consumer representatives or communities.

Our priority focus is on consumer engagement that influences and leads improvements and delivers better health outcomes for all Queenslanders. We achieve this through our Queensland-wide health consumer network, tailored training and skills development programs, and maximising opportunities for consumer representation at all levels of the health system.

Consumer engagement is when health consumers actively participate in their own healthcare and in health policy, planning, service delivery and evaluation at service and agency levels.

HCQ | HEALTH CONSUMERS QUEENSLAND

STRATEGIC DIRECTION 2018–2023

MISSION
Health Consumers Queensland enables and empowers consumers to influence, lead and drive better health outcomes

VISION
Consumers and community partnering with the health system for consumer-centred health care for all Queenslanders

VALUES
Leadership
Positive Impact
Fairness
Innovation
Partnership
Zing/Zest

Our Six Strategic Objectives

1. Enabling health consumers and healthcare staff statewide
We build consumer, staff and system capacity to design a health system together through collaborative, integrated and consumer-centred approaches by providing support, strategic advice, training and advocacy.

2. Acting as an agent of change for consumer-centred health care
In partnership with consumers and healthcare staff, we act as a strong voice on system wide issues to influence key decision makers, policies and models of care to deliver a high quality consumer-centred health care system for all Queenslanders.

3. Enhancing effective partnerships
We develop and grow effective organisational partnerships locally, nationally and internationally to achieve consumer-centred health care for all Queenslanders.

4. Building and using evidence
We support consumers and staff to be involved in co-creating the evidence base for health system development and transformation. We act on the evidence of the human lived experience of the health system to build capacity of consumers and to leverage system change.

5. Being transparent and enduring
We demonstrate transparency and responsiveness on behalf of consumers, community and our funders. We maintain strong leadership and governance to assure organisational sustainability and longevity. We support the passion, energy and courage of our staff and members of our Network.

6. Addressing the social determinants of health
We acknowledge that systemic reform of the health system requires recognising the social determinants of health and co-designing models of care that address them.

Areas of Focus

Our areas of focus in implementing our strategic objectives

In partnership with consumers (including vulnerable groups) and staff, we act as a strong voice on system wide issues such as:

- **Healthcare Rights:** Breaches of healthcare rights which prevent fair, just and affordable access to healthcare;
- **Quality & Safety:** Where quality and safety and/or consumer experiences are of concern;
- **Healthcare Standards:** Embedding healthcare standards around consumer engagement, comprehensive care and health literacy; or
- **Systemic Issues:** Complex, difficult or contentious systemic issues.