ST VINCENT'S HEALTH AUSTRALIA
UNDER THE STEWARDSHIP OF MARY AIKENHEAD MINISTRIES

SVHA Submission: *Queensland Parliamentary Inquiry into Aged Care, Palliative Care and Voluntary Assisted Dying*

Project Sponsor

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1. Introduction

1.1 Background

St Vincent's Health Australia

St Vincent's Health Australia (SVHA) is the nation's largest not-for-profit health and aged care provider. We operate two public hospitals, 10 private hospitals and 17 aged care facilities in Queensland, New South Wales and Victoria. Along with three co-located research institutes – the Victor Chang Cardiac Research Institute, the Garvan Institute of Medical Research and St Vincent's Institute of Medical Research – we work in close partnership with other research bodies, universities, and health care providers.

SVHA has been providing health care in Australia for 160 years, since our first hospital was established in Sydney in 1857 by the Sisters of Charity. When the first five Sisters arrived in Australia in 1838 they carried with them the vision of their Founder, Mary Aikenhead, to reach out to all in need of care and particularly to the poor and vulnerable. It is the legacy entrusted to us by the Sisters of Charity that continues to inspire St Vincent's Health Australia to strengthen and grow our mission.

SVHA employs over 19,000 staff and operates more than 2,600 hospital beds and 1,100 residential aged care places. In our hospitals, we provide more than 1 million episodes of care for patients each year.

We are a clinical and education leader with a national and international reputation in medical research. Our areas of expertise include mental health; drug and alcohol services; homeless health; prisoner health; heart lung transplantation; bone marrow transplantation; cardiology; neurosurgery; cancer; clinical genomics; HIV medicine; palliative care; respiratory medicine; and aged psychiatry.

In Queensland, St Vincent's Private Hospital Brisbane (SVPHB) operates the largest Palliative Care (PC) inpatient facility in the State, a 40 bed specialist palliative care (SPC) inpatient unit with shared public and private beds. Since its inception in 1958, this hospital site - previously known as Mount Olivet - has been providing Palliative Care Services and Aged Care Services to the people of South East Queensland.

SVPHB provides a multidisciplinary community specialist palliative care service for patients within the Brisbane City Local Government area, including home visits 24 hours a day, seven days a week when needed. Between our community specialist palliative care service and our inpatient palliative care unit we provide a seamless model of transition, where patients can be directly admitted into a bed 24 hours a day, 7 days per week.

St Vincent's Health Australia currently proudly owns and operates over 17 aged care communities under the St Vincent's Care Services (SVCS) banner in communities across Queensland, New South Wales and Victoria. SVCS also manages (on behalf of a Religious Congregation) a residential aged care community located in Cronulla, Sydney.

Across all its aged care communities, SVCS currently provides 1,622 residential aged care beds (there are more than 200,000 residential aged care places in Australia), 330 retirement living units, 230 home care places, 175 CHSP and 61 private clients which represents support to over 2,000 elderly Australians.

Close to 40% of SVCS's residential aged care residents are from low means or disadvantaged backgrounds. These residents are provided with supported accommodation through a Government-funded Commonwealth payment that covers all or part of their accommodation charges.

The organisation's first South East Queensland aged care community opened back in 1977 at Kangaroo Point, Brisbane. Since 1977, SVCS have increased their commitment to the elderly in Queensland by operating nine communities aged care and/or independent living. These communities provide 889 residential aged care beds and 228 retirement living units. In addition, SVCS provide services to the elderly through home care, CHSP and private clients.

SVCS is currently in the process of finalising the transition of a further two South East Queensland aged care communities that will add an additional 189 residential aged care beds and 256 retirement village units to its current portfolio.

1.2 Executive Summary

SVHA is well placed with our extensive experience in delivering quality hospital, health and aged care to provide feedback to the questions posed in the Issues Paper issued by the Parliamentary Inquiry into Aged Care, Palliative Care and Voluntary Assisted Dying in 2019.

SVHA understands the interface between end of life planning and access to quality and culturally appropriate palliative care services in a large decentralised state such as Queensland. SVHA supports appropriate end of life care as outlined by the World Medical Association.

SVHA does not support the introduction of Voluntary Assisted Dying (VAD) in Queensland. Instead, we are strong advocates for better planning, investment and access to palliative care and end of life services across the State.

SVHA welcomes the chance to engage with the Parliamentary Inquiry as it provides us with an opportunity to emphasise Queensland's unique position to introduce a world class service end of life care system which:

- Responds to the needs of Queenslanders and provides access to quality health care and palliative care support regardless of where they live
- Encourages better coordination across health and aged care systems and supports holistic care of patients and eradicates red tape and administrative duplication between agencies and levels of Government
- Supports the development of, training and retention of a skilled end of life management workforce
- Draws on, and makes use of technology and other innovations to deliver advice, support and services to regional and remote Queenslanders who are entering their end of life stage to better support them
- Considers alternative models of end of life care models which incorporate the diverse cultural and geographical challenges of the State and
- Incorporates research into new and innovative care for people at the end of life.

More importantly, SVHA believes this Inquiry provides an opportunity for Queensland to develop a whole-of-state end of life strategy. Despite "which level of Government" funds services, SVHA's position is the individual's needs must be at the centre of service planning, delivery and care.

A key plank of this strategy should be investment in public education about what constitutes best practice end of life and palliative care as well as a state-wide workforce development and training plan which encourages end of life and aged care as a viable career option.

The following submission has been informed by representatives, including our leading palliative and end-of-life care specialists, other clinical and non-clinical leaders, from our public and private hospitals and aged care facilities. This submission sets out SVHA's advice regarding aged care, palliative care and voluntary assisted dying.

More importantly, our submission puts the individual at the centre of our advice to the Inquiry. The emphasis of care should be on the individual and not "who and which level of Government provides the care".

We must never forget that future models of end of life and aged care services must always take into account the needs of the individual, families and their communities, and we must always provide as well, for those amongst our communities that cannot afford private health care, as they approach their end of life stage.

1.3 Table summary of key points in Submission

Topic	Submission
End of Life Stage	The volume and complexity of Queensland’s health and aged care needs is changing significantly. SVHA’s position is the individual’s needs must be always be at the centre of service planning, delivery and care. SVHA calls for better coordination across health and aged care systems and supports holistic care of individuals. SVHA calls for eradication of red tape and administrative duplication between primary, acute and aged care agencies and levels of Government. (State and Commonwealth) SVHA supports the opportunity this Inquiry offers to develop a new “master plan” for coordinating care and support to Queenslanders during their end of life stage as a model and example for the rest of Australia. SVHA calls for investment in alternative models of care and service, informed by local community and cultural considerations. SVHA supports the incorporation of research findings/evidence into new and innovative care for people at the end of life stage.
Skilled and qualified health workforce	SVHA supports the development of training, development and retention of a skilled end of life management workforce across medical, aged care and community sectors.
Public Education	SVHA calls on the State Government to invest in better public education across the spectrum of aged care, palliative care and bereavement management. SVHA encourages the State Government to support the establishment of wellness hubs – such hubs could act as a source of information and advice to families and friends of those experiencing ageing or advancing special needs of a loved one.

Aged Care	SVHA supports improving the transitioning of individuals between different systems and agencies to minimise impact on their health and quality of life. SVHA believes the State has a role to play in improving the infrastructure, service and workforce conditions to attract health professionals and aged care workers to the sector. SVHAs view is the coordination of care of people across “systems” – from GPs, to hospitals to aged care – needs to be improved and strengthened and this involves strengthening the coordination between both levels of Government (State and Federal).
Palliative Care	Euthanasia/VAD is not part of palliative care practice. Palliative care in Queensland needs be better resourced. This Inquiry has an opportunity to firstly evolve the current design, planning, funding and service delivery models for palliative care in Queensland so that the needs of its citizens can be better met. Demand for palliative and end-of-life services will only increase as Queensland’s population increases and ages. SVHA advocates that access to direct admission to inpatient palliative care facilities 24/7 and advice needs to be invested in to better support the needs of individuals and their families, health practitioners and residential aged care facilities. Future planning for services must involve metropolitan and rurally based Aboriginal and Torres Strait Islander representatives in the design and delivery end of life services, enabling people to die on country or in a place that is culturally safe. SVHA supports increased investment in public education about palliative care, as a means of empowering the community to understand what options they have available to them at this stage of life. A new workforce strategy should be developed and implemented to grow the palliative care workforce across Queensland. Bereavement care is integral to palliative care and all palliative care services should be funded and staff to provide a comprehensive bereavement service to all patients and their families/community.

Voluntary Assisted Dying (VAD)	SVHA does not support the introduction of VAD in Queensland. SVHA advocates for better planning, investment and access to palliative care and end of life services across the State of Queensland. SVHA believes the state of Queensland has an opportunity to firstly invest and put in place a world class palliative care and end of life care system.

Queensland’s Aged Care Services System

Please find following SVHA’s responses to the Issues Paper Questions.

In Australia, aged care services are predominantly funded by the Australian Government with a smaller number of aged care places funded by states and territories, including the Queensland Government. We also note this Inquiry is aware of the current Australian Government’s *Royal Commission into Aged Care Quality and Safety*.

1) Is the aged care system meeting the current needs of older Queenslanders, including those people with special needs? Why or why not?

Understanding what the aged care system can offer can be daunting to elderly people and their families. In our experience, some residents can find themselves ‘stuck’ in parts of the system which can greatly affect their health and well-being at a time in their lives when they are vulnerable. For elderly people and their families, the challenges accessing appropriate aged care servicing are compounded when clients are based in regional and rural Queensland where there can be reduced availability of aged care facilities and support.

Australia’s current aged care system offers a mix of different levels of Federal and State Government funding, eligibility rules and requirements. What this means in practice, is an individual is required to engage and coordinate at their time of need, appointments and documentation across a wide range of health and community-based providers over the primary health, acute care, human services, and aged care portfolios, all of which have differing administrative processes and requirements, as well as differing timeframes for approval of items, such as home care packages. The amount of “administrative work and coordination” that must occur across many agencies can be unnecessarily daunting and overwhelming. Following are some the ways the system struggles to meet the needs of older Queenslanders, including those people with special needs:

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

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

- ***Distribution and lack of specialised and skilled aged care workforce*** - A key challenge in Queensland's aged care system is the uneven distribution of specialised, well-trained and job-ready professionals who are experienced in geriatric care, ranging from healthcare workers to personal care/community care workers. It is critical that residents have access to the necessary skillset in the workforce, particularly for those clients who may be experiencing disorders such as dementia and/or requiring palliative care when they need it.

- ***Access to GPs and specialists*** – poor access to GPs, lack of GPs specialising in aged care and waiting lists for specialists, especially in regional/remote areas where there are fewer GPs and specialists impacts on residents and those living in their homes.

- ***Increasing number of clients with cognitive impairment/dementia ageing and in need of specialist infrastructure catering for special needs clients*** – with challenging complex behaviours, changing conditions particularly amongst our elderly population, there will be a need to strengthen the skills, training and experience of the aged care workforce, as well as update and/or build better purpose built facilities so they are able to deliver the appropriate care to both elderly residents, and for those with special needs that need to be accommodated within a residential service**.**

2) Are the current waiting times for both residential and home care places adequately meeting the needs of older Queenslanders?

SVHA notes that recent industry data indicates industry occupancy rates for aged care are declining, suggesting there is bed capacity in the current system. As well, the Federal Government in 2018/2019 announced an additional 10,000 Home Care packages to address increasing demand for home care support. While such figures indicate that there is some additional home care package and bed capacity in the state system, it is SVHA's experience that the ability of residents to access the right care, with the right carers, in their location is still a challenge due to key factors such as:

- **Length of time for aged care approvals** - due to delays in approval of home care packages across all levels – basic to high – it is difficult for individuals to access the right care in their location in a timely manner and it results in individuals waiting many weeks for a response.

- **Impact of rural and regional living** - with such a decentralised population, the distribution of facilities and an appropriately skilled workforce is a strategic challenge

> for Queensland. So, while on paper and/or in data there are indications the “numbers are right” to address demand, the distribution of service providers and beds, and the presence of a local well-trained and experienced aged care workforce, needs to be factored into the planning of the state’s aged care system.

From our experience the impact of these factors can directly impact on the physical and emotional health of individuals and families.

In the future, applications for home care and residential support packages need to be streamlined and better coordinated through investment in back-end systems so individuals and their families are not left “hanging” or “hoping” for confirmation of support over many weeks at a time when people need support the most.

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?

SVHA notes the Australian Government’s *Royal Commission into Aged Care Quality and Safety* is currently canvassing the views of the community about whether Australia’s residential, home care and other aged care services are meeting their expectations. SVHA has made a Submission to the Commission.

SVHA’s Queensland aged care facilities operate under the 44 expected outcomes of the current Australian Aged Care Quality Standards. Our facilities have in place the required clinical, management, workforce and facility procedures, consumer practices, and safety and quality frameworks to ensure our care meets the required standards.

It is our view, however, that often the standards we and other aged care providers are required to meet do not always equate with resident expectations regarding the type of holistic care they or their families desire. Standards are an important benchmark for the delivery of safe and quality care, however facilities in the future need to be supported to be able to offer the holistic care that residents and their families expect.

We note that aged care facilities are somebody’s home.

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?

By 2056, those aged over 65 will increase from 15 per cent to 22 per cent and the proportion of people aged over 85 will double[1]. The projections indicate that growth in this age bracket will likely translate into growth in other chronic diseases such as obesity, diabetes and dementia.

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[1] Catholic Heath Australia (CHA): Palliative Care in the Catholic Sector Report March 2019; page 7 Source: ABS 3222.0 – Population Projections, Australia, 2012 (base) to 2101*

SVHA believes there is an opportunity for the Queensland Government to lead the development of a comprehensive 'master plan' for aged care and end of life care in the state, in partnership with the Federal Government, local community organisations, and service providers to:

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

While aged care services are predominantly funded by the Australian Government, this Inquiry provides an opportunity for the two levels of Government to work together in a complementary manner to coordinate planning and investment in Queensland's aged care sector – in order to better meet the needs of Queenslanders as a model and example for the rest of Australia.

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?

As outlined in Question 2, SVHA believes that the distribution of facilities and available primary health, community based support services should be factored into the discussion about the number and location of, aged care beds for different levels of care. Future funding and systems should have better flexibility to support the ranges of care needed when the demand arises so resident's and people ageing in their homes have their needs met.

6) Are adequate numbers of home care packages available in areas at the levels required?

SVHA notes the Australian Government released extra home care packages in 2018/2019 nationally however, from our experience:

- the packages are not being released fast enough
- in some areas, it is difficult to support the implementation of the packages due to a lack of available and localised personal care/specialist aged care workforce
- funding does not extend to resolving underservicing in some areas. For example, it does not take into account the travel time of an organisation's staff to an individual's home.

Because of these impediments, SVHA believes there needs to be some adjustments to the contracting and funding conditions for service providers, to afford them an opportunity to better service, recruit and train an experienced aged care support workforce which can better support elderly people and those with special needs in aged care based in regional and rural Queensland.

7) Are there sufficient staff in the aged care sector to meet current and future workloads?

The current and future supply of a well-trained, skilled and job ready workforce for the aged care sector is currently subject to extensive examination by the *Royal Commission into Aged Care Quality and Safety.* In our response to the Commission's provider survey, SVHA advocated that the critical issues underpinning future workloads in the aged care sector are:

- **Strengthening training and job readiness pathways** – universities and vocational education institutions must graduate students with knowledge and skills that meet the future skill requirements of the aged care sector. This should include incorporating new modules of learning with an emphasis on dementia and palliative care.

- **Improving the workforce conditions to attract health professionals and aged care workers to the sector** – this would help attract and retain a qualified and committed workforce and help address high staff turnover and heavy workloads.

- **Improving infrastructure and services**– in hospitals and aged care facilities so that resident's needs between the systems can be better supported by well-trained and qualified staff.

- **Better promotion of the aged care sector –** the Australian aged care sector is not always viewed as an attractive industry for a career. Critical to the future workforce pipeline to meet need in the aged care services, is the promotion of the sector as a beneficial place to work, with well-supported training, standards, positive work culture and service delivery.

8) Is the mix of staff appropriate for different settings within the aged care sector?

Overall our experience is that the mix of highly skilled and job ready staff are difficult to retain in the aged care sector.

Under the current funding framework, it can be difficult for an aged care facility to put in place a staffing mix model which meets the mix of resident needs.

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

- Resident choice when it comes to health care can be impacted when there is poor access to local GPs (especially in regional/remote areas).

- Waiting lists for geriatric specialists are extensive. Specialists do not always conduct service visits which is a challenge for residents and facilities, as well as for their families who often must take them to appointments.

- The current funding model does not afford aged care facilities with the opportunity to staff services with more registered nurses, nurse practitioners, allied health, counselling and social work professionals.

- A lack of local GPs specialising in aged care. There is often a lack of interest amongst the GP/Primary Health sector in developing specialised medical skills relating to the elderly demographic. Given Queensland has put in place a rural GP training program, SVHA would be supportive of additional learning and training in caring for the elderly being incorporated in this program.

9) Do aged care staff receive training that is appropriate and adequate to prepare them for the work?

As is the case in many industries, staff may have completed their formal qualifications for training but they also need to be “job-ready” upon graduation.

SVHA’s view is that there is an opportunity to evolve the current vocational education and health professional pathways so that individuals can obtain valuable work experience and exposure to this sector early and more frequently throughout their training, including when GPs complete specialist training.

This may help improve number of health professionals and community care workers considering a career in aged care as well with the supply and retention of a skilled, job-ready, and committed workforce.

One idea to improve the job readiness of aged care staff includes evolving current medical, health and community care training frameworks so that students have earlier placements and additional modules in aged care services in their course.

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?

There is a substantial cost to Queensland’s public health system if elderly persons are left waiting in hospital wards while a suitable aged care place is found for them.

While we understand this question gives rise to a wider discussion about ‘State vs Commonwealth’ funding responsibilities, it is important to see the transition of an elderly person from hospital into aged care as involving the same spectrum of care.

An individual in this position is less likely to be worried about which level of Government “pays for what” and just wants a continuity of good quality care and access to support so their quality of life is maintained with dignity and respect.

It is our view that the coordination of care of people across “systems” – from GPs, to hospitals to aged care – needs to be improved and strengthened. Both levels of Government need to ensure the necessary funding and frameworks are in place, and administrative burden and roadblocks removed, so that individuals making the transition are well supported, and service providers are afforded an opportunity to deliver quality and person-centred care.

To do this, one suggestion SVHA proposes relates to shared access to electronic medical management systems (EMSs). EMS in the future could better support discharge and health care planning between hospitals, GPs and aged care facilities to help improve coordination of information and care across different agencies.

However, this idea is not new, and nor is the point that levels of Government need to work differently together and evolve their systems to be better at responding to the needs of individuals, particularly at a vulnerable time in their lives.

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

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

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

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?

The volume and complexity of Queensland's health and aged care needs will change significantly over the next thirty years.

SVHA understands that in Australia, by 2056, those aged over 65 will increase from 15 per cent to 22 per cent and the proportion of people aged over 85 will double. Further, Australia has growing rates of chronic disease such as diabetes, obesity and dementia[2].

According to Queensland's population projections 2018 edition, produced by the Office of Government Statistician Queensland Treasury, the age structure of the Queensland population is projected to change significantly in the 50–year period to 2066.

While there will be increasing numbers of persons in all age groups including school–aged children, a significant increase in both the number and proportion of people in older age groups is projected. Queenslanders aged 65 years and older accounted for 14.7% of the

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[2] Catholic Heath Australia (CHA): Palliative Care in the Catholic Sector Report March 2019; page 7 Source: ABS 3222.0 – Population Projections, Australia, 2012 (base) to 2101*

population in 2016—this is projected to increase to 23.8% under the high series, and 25.8% under the low series by 2066[3].

Based on these projections, in the future, we expect to see an increasing number of residents with cognitive impairment/dementia which means an increase in complex behaviours (e.g.: aggression, intrusive behaviour).

This will mean, for example, that GPs, nurses and other support workers who work with elderly people may not have the specialist knowledge specific to dementia and require input from a geriatrician or access to further training in this field.

SVHA advocates there is a real opportunity for Queensland to create a “master plan” for its future aged and home care system but it will require:

- A different approach to funding and coordinating aged care and complementary health services between federal and state levels of Government
- Encouraging GPs and registered nurses to take an interest in aged care services and uptake training and employment in this field
- Changing the funding model so that GPs are supported to provide more primary care services for residential aged care
- A concerted state-wide strategy to holistically manage the health and care needs of over 65s across the state
- An increase in dementia education and training and care support for health professionals and community care workers
- Improvement in the interplay between specialities and other part of the health system, such as allied health
- Funding and support for transport options to help residents maintain connection with their community and attend hospital/specialist appointments
- Trialling new models such as “hospital in the aged care facility “or increasing the number of nurse practitioners working in the aged care sector and affording them the opportunity to access MBS items
- Increasing the use of technology in the delivery of aged care services.

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

SVHA believes it’s time to develop an aged care master plan for Queensland which addresses:

- Difficulties in establishing and maintaining partnerships with hospitals by putting in place services that pursue a collaborative approach to resident care.
- Poor communication between hospital and aged care facilities, which is often reflected in the way hospitals discharge aged care residents, a process that often involves little or no consultation with the aged care providers. If the hospital discharge process is improved, better follow up care will be the flow on effect.

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[3] Queensland Government population projections, 2018 edition: Queensland; Queensland Treasury

- Trialling new models such as “hospital in the aged care facility” or increasing the number of nurse practitioners working in the aged care sector and affording them the opportunity to access MBS items.
- Improving the use of technology, particularly for discharge from hospital. For example, we believe better technology could help with tracking a resident’s appropriate medication upon discharge. Currently, a hospital’s poorly managed discharge of an elderly person to an aged care facility – without the appropriate details around their ongoing medication – can result in up to two days wait as the regular GP has to review the prescription first and provide clearance.
- The difficulties in organising follow up care post hospital and other health professional sessions
- Improving regional and remote acute care access
- The difficulties in accessing psychogeriatric care for residents because of the limited availability of services
- Improving specialist mental health care for older Australians and
- Improving dental and other health services and addressing the difficulty encountered with urgent referrals.

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

The rise of patient-centred care in health and aged care services design, means future residents of aged care services will hold a range of ideas for what alternative models should be considered.

SVHA strongly supports that future models should always take into consideration the voice of the resident and their families as part of the service design. Following are a few ideas for future models informed by our experiences of delivering aged care services in Queensland:

- **Use of different mix of health staff** – important that health professionals other than medical specialists are provided with up skilling and training in areas such as aged care, gerontology, dementia management, pain management, wound care, continence management and other chronic diseases.
  In the future, nurse-led teams consisting of other allied health support are an option to consider. These teams could coordinate with local GPs and aged care services to help support individuals in their home care environment.

- **Opportunity to establish wellness hubs** – such hubs could act as a source of information and advice to families and friends of those experiencing the ageing or advancing special needs of a loved one. These hubs could help promote the use of technology, raise community awareness about care and support needs, and de-stigmatise the ageing process, especially for those individuals keen to remain in their home with support.

- **Serving Aboriginal and Torres Strait Islander residents better** - Funders and facilities should be sensitive to the needs of Aboriginal and Torres Strait Islander peoples and support alternatives to residential care, understanding the impact of trauma arising from re-institutionalisation. Recent AIHW data forecasts that by 2023, all remaining Stolen Generation survivors will be eligible for aged care. There is a need to support alternative and culturally appropriate care to those who experienced significant trauma in their childhood due to forcible removal, at their last stage of life.[4]

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

Technology, robotics, artificial intelligence and the expansion of telehealth will assist future aged and home care services to better plan the care for elderly people and to intervene earlier when it comes to their health needs.

An increased use of technology will also help providers proactively manage individual's needs as well as empower them to engage in their own monitoring, condition management, and connect and engage with other individual's online, enlisting them to be part of their own care.

16) What are the key priorities for the future?

As outlined in Question 12, the age structure of the Queensland population is projected to change significantly in the 50–year period to 2066.[5]

SVHA's view is the gap between aged care funding and resident's expectations, needs to be addressed. Queensland has a real opportunity to trial a new way forward in areas such as:

- **Information sharing** – across systems – needs infrastructure investment, better integration, real-time discharging information, and access to hospital records. (e.g.: the rolling out of Queensland's new EMR system presents an opportunity for this to occur). This will address many current challenges, including unavoidable admissions.
- **Improve the mix of the aged care workforce** - including trialling and funding mobile allied health and dental services to aged care facilities.
- **Improve access to medical support** - such as after hours and palliative care, in regional and remote settings.
- **Improve access to pharmaceutical services.**
- **Support and fund regular education in dementia and palliative care for all staf**f - This could include funding pilots which train nurse practitioners with advanced skills in geriatrics and with prescribing rights to all aged care facilities, which would improve timely access to medical care, reduce unnecessary emergency department presentations, and improve follow up care.
- **Increased use of nurse practitioners-** the provision of palliative and wound care, particularly in regional areas, would also help.
  Embedding advance care planning into aged care facilities – both through public education of planning for your own future, and through education to providers of aged care facilities so people are given the opportunity to remain in place if they wish to have end of life care in their aged care facility.

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[4] Healing Foundation 19 February 2019 Media Release "Stolen Generations want a commitment on aged care"

[5] Queensland Government population projections, 2018 edition: Queensland; Queensland Treasury

Queensland's Palliative Care Services

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

St Vincent's Private Hospital Brisbane (SVPHB) provides inpatient in-hospital palliative care services to private and public patients. SVPHB has a 40-bed inpatient unit dedicated to the care of public palliative care inpatients within the Metro South Queensland Health zone of Brisbane, and privately insured patients.

We provide a multidisciplinary community specialist palliative care service for patients within the Brisbane City Local Government area, including nurse visitations 24 hours a day, seven days a week when needed. SVPHB Medical Specialists provide consultation liaison services to St Vincent's Private Hospital Northside. The inpatient/community service is fully integrated and patients are able to be admitted directly into an inpatient bed 24 hours a day, seven days per week.

SVPHB initiates and publishes high quality research with the aim of improving patient outcomes. Recent research has included increasing the understanding of patient and carer journeys to and through palliative care (including participants from culturally and linguistically diverse communities), innovative models of community palliative care (via a partnership with Bupa), documenting changes in patient's preferred place of death, quality use of medications and reasons for admission to hospital from community palliative care.

SVPHB is a member of the Palliative Care Clinical Studies Collaborative, Cancer Symptom Trials and Queensland Palliative Care Research Group.

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

High quality palliative care needs to be properly resourced in Queensland.

Although the State has some high quality services, many Queenslanders miss out because of inadequate resourcing and lack of specialist access to services. This Inquiry has an opportunity to evolve the current design, planning, funding and service delivery models for palliative care in Queensland so that the needs of its citizens can be better met.

For example, while 70% of people say they want to die at home, about half of all deaths in Queensland occur in hospital, costing the state approximately $776 million per year.[6]

Queensland is a state with a dispersed decentralised population. As a result, there are gaps in the provision of palliative care across Queensland, including lack of available experienced palliative care professionals and care support workers in many areas of regional, rural and remote areas.

However, even in a capital city like Brisbane, there is inequity in current service provision.

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[6] "Time to build a Palliative Care Culture in Queensland Manifesto 2017/2018"; Palliative Care Queensland; 2017, page 3

For example, public patients in the Metro South HHS area have access to inpatient palliative care through SVPHB's agreement with the Metro South. However Metro North HHS will not pay for any public patients in the Metro North area who wish to be admitted as an inpatient to SVPHB. This means patients and families have to sometimes travel a longer distance to another palliative care facility. Of particular concern are the number of tenuously-housed and vulnerable patients in Brisbane's inner city who are unable to access inpatient palliative care close to their home.

A second example is that for patients on the SVPHB community specialist palliative care service there is inequity in the payment and access to equipment at the end of life. Metro South HHS will subsidise and provide access to equipment but Metro North HHS will not do that for patients on the same service living in the Metro North area.

While from the state health agency's administrative perspective the zone boundaries are important, in practice they create a significant deficit in the care of people requiring palliative care, just because they happen to be based in a particular geographical location.

Patients, their families and carers want to access the best palliative care when and where they need it. They don't always consider the zone boundaries that dictate their service access. This is not an example of fair and equitable access to palliative care.

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

Palliative care is a core component of healthcare. In Australia, one in six public acute hospitals have a palliative care unit.[7]

Queensland palliative care services have a reputation of providing high quality care. At SVPHB, our palliative care services adhere to clinical guidelines in palliative care and ACHS standards. We participate in the Palliative Care Outcomes Collaborative (PCOC). At SVPHB we are also accredited to train palliative medicine specialists through the Royal Australasian College of Physicians (both with advanced trainees and diploma candidates).

There are many misconceptions around palliative care that members of the community may have, including that it is simply about dying.

Palliative care improves the quality of life of patients and their families facing life-threatening illness. It prevents and relieves suffering through the early identification, assessment and treatment of pain and other symptoms, including physical, emotional, psychosocial and spiritual.[8]

Palliative care is not about shortening or prolonging life, it is about helping patients have the best life possible.

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[7] Australian Institute of Health and Welfare, *Palliative Care Services in Australia*, May 2017

[8] World Health Organisation's definition of palliative care

Palliative care:

- Promotes **patient independence** by helping people decide which treatments they would like to continue, and which have become too burdensome and should be stopped.
- Promotes a **multidisciplinary approach –** specialists, nurses and allied health workers work together to ease pain and other symptoms, providing psychological and emotional support, and bereavement support.
- Happens in a **range of locations** – the home, hospital, hospice, and/or aged care facility.
- Is for anyone diagnosed with an advanced, life-threatening illness – such as cancer, but also other non-malignant conditions, such as neuromuscular disorders – and should be routinely introduced **alongside active treatment**.

There is strong evidence on the benefits of palliative care in relieving symptoms and pain, but also improving quality of life, mood, satisfaction with care (for patients[9] and their family carers[10]) and, in some cases, even survival.[11]

Among the thousands of deaths our palliative care teams witness, patients' symptoms are well-managed, people are able to communicate their preferences, and say their farewells. It's common for families to comment on how peaceful a death was.

Misconceptions about palliative care

There are many misconceptions about palliative care.

One of the biggest misconceptions is that euthanasia is part of palliative care and is performed in palliative care facilities. Euthanasia/VAD is not part of palliative care practice.

Addressing another misconception, there is sometimes a viewpoint that many patients are given 'terminal sedation' at the end of life to hasten a patient's death. And that somehow 'terminal sedation' is euthanasia by stealth.

The use of opioids and sedative medication at the end of life to relieve distress, suffering and symptoms is an important component of palliative care. An aim of palliative care is for patients and families to live as well as possible and then die as well as possible. Such use of medications at the end of life has been extensively researched – including by SVPHB

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[9] Parikh RB, Kirch RA, Smith TJ, Temel JS. *Early specialty palliative care — translating data in oncology into practice*. New England Journal of Medicine, 2013; 369: 2347-51.

[10] Christakis NA, Iwashyna TJ. *The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses*. Social Science and Medicine, 2003; 57: 465-475.

[11] Temel J, et al, *Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer*, New England Journal of Medicine, 2010; 363:733-742.

clinicians[12]. All the research in this area has consistently shown that the use of opioid and sedative medication, used within clinical guidelines, does not shorten a patient's life.

Many misconceptions around palliative care are held by health professionals. Too often referrals to palliative care are made by clinicians when a person is very close to the end of life or when death is imminent. This means patients miss out on the benefits that palliative care can deliver throughout their treatment. There can be concerns by health professionals that a referral to palliative care means 'giving up' or 'losing hope'. In fact the opposite is true and there is now extensive research showing that early referral to palliative care for malignant and non-malignant conditions can improve quality of life.[13],[14]

Specialist palliative care services are not involved in every expected death, and there can be wide variation in the quality of care provided where there has not been training or experience in palliative and end of life care.

SVHA supports increased investment in public education about end of life care, including palliative care, as a means of empowering the community to understand what options they have available to them at this stage of life

Further consideration needs to be given to growing the palliative care workforce in Queensland.

Palliative care is an important area of health, and there is an opportunity to develop a workforce strategy that promotes providing further training, up skilling and access to specialist support for health and community-based services in those locations where there is no specific palliative care service

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?

Demand for palliative and end-of-life services will only increase as Queensland's population increases and ages. In the future, some of the key factors that should be considered when planning to meet the demand for palliative care and end-of-life services in Queensland include:

- The ability to provide integrated palliative care for patients with malignant and non-malignant conditions across the spectrum of care – hospital, community, aged care facilities
- Provision of ongoing training and up skilling to local health and community care workers in areas where there is no stand-alone palliative care service unit

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[12] Good PD, Ravenscroft PJ, Cavenagh J. Effects of opioids and sedatives on survival in an Australian inpatient palliative care population. Internal medicine journal. 2005 Sep;35(9):512-7.

[13] Temel J, et al, Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer, New England Journal of Medicine, 2010; 363:733-742.

[14] Higginson IJ, Bausewein C, Reilly CC, Gao W, Gysels M, Dzingina M, McCrone P, Booth S, Jolley CJ, Moxham J. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. The Lancet Respiratory Medicine. 2014 Dec 1;2(12):979-87

- More involvement and engagement of general practitioners, including access to after hours and home visits for palliative care patients
- The need to increase the capacity of specialist palliative care services to support residential aged care facilities
- The role of technology such as a means of supporting services, health professionals, individuals and their families particularly in their homes.

From our experience, the majority of patients admitted to current services have a cancer-related diagnosis but this will change as people with life limiting conditions are increasingly referred to palliative care.

Equitable access to community palliative care requires investment in a multidisciplinary team providing holistic care. One of the key tenants of quality palliative care is holistic care of a person, and that includes seeing the person within their social context.

This is actually what personalised care is: recognising the individual needs of patients.

The only way to truly provide this care is via a multidisciplinary team because no one practitioner can provide this care. We see it as important to have a team involved including (but is not limited to) doctors, nurses, social workers, physiotherapists, occupational therapists, psychologists, counsellors and pastoral care workers.

It is also important to have a general practitioner as a constant in a patient's care, including having the ability to provide home visits. Where people live in communities that have limited access to medical care, it is important to up skill other health workers in providing palliative care.

Bereavement care is also integral to palliative care and all palliative care services should be funded and have staff to provide a comprehensive bereavement service to all patients.

In the future, it will be important to support a well-trained health workforce to support palliative care in Queensland. For example, SVPHB is a training facility for new Palliative Medicine Specialists.

The current Palliative Care Australia recommendations for delivery of Palliative Care include having a ratio of 2 FTE Palliative Medicine Specialists for every 100,000 population. That would mean approximately 100 FTE Palliative Medicine Specialists in Queensland. Current estimates suggest that there are approximately 35 FTE in Queensland, meaning there is a significant shortfall in staffing.[15]

SVHA's position is that there is an urgent need to increase training positions and Palliative Medicine Positions across the state to meet future demand, as the shortfall is particularly acute in regional, rural and remote areas.

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[15] Queensland Palliative Medicine Training Oversight Committee, Integrated training pathway and palliative medicine workforce report. August 2018

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

SVHA's view is that all patients should be able to access palliative care based on their needs, not determined by diagnosis, prognosis, and geography. There needs to be different service and care options available for patients across the state, and support should be able to be accessed for in home care.

This means designing and funding different models of palliative care to suit the needs of local communities as opposed to utilising a "one size fits all" approach. Our experience shows that there is a need for greater flexibility for patients to access community palliative care programs. SVHA offers the following examples to illustrate our point:

- There needs to be equitable access to both inpatient and community palliative care irrespective of where a person lives. Some simple examples of inequity within the Brisbane Metro area includes that public patients residing in Metro North cannot be admitted to SVPHB inpatient facilities – even though for many dying patients that is the closest palliative care facility to them
- Funding and provision of equipment such as hospital beds – there is variation to access depending whether a patient lives north or south of the Brisbane River
- All publicly and privately funded palliative care services should have clear KPIs to which they are accountable
- We advocate that people requiring palliative care services should have:
    - Access to direct admission to inpatient palliative care facilities 24/7;
    - Access to specialist palliative care service advice (either in person or via videoconference facilities) 24/7; and
    - Access to specialist community and home-based care.

In addition, every cancer multidisciplinary team meeting should have a Palliative Medicine Specialist and/or a Palliative Care Nurse as a core member of the team to ensure appropriate and timely referral and improved outcomes for patients and their families.

In our view, if all patients with a life-limiting illness had access to the above services, and KPIs were achieved across Queensland, there would be a substantial improvement in palliative care delivery and outcomes.

To provide an example of SVHA supporting a trial of new model of palliative care, over the last two years, SVPHB in partnership with Bupa has conducted a very successful pilot program to provide palliative care services for Bupa members in their homes in the community. This program aimed to increase access to palliative care services for Bupa patients and their carers and provide them with greater support in the community. The results demonstrated:

- Increased home death rates
- Decreased acute hospital death rates
- Very high preferred place of death achieved
- Very high patient/carer satisfaction
- Substantial cost saving per patient[16]

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[16] SVHA could formally present the outcomes of this two-year pilot program if required.

One of the more important findings from this study was that a preference for a home death depended on service availability and expectations of patient and family. It showed that if there is more support in the community available to patients and carers then more people want to die at home, and more people actually do die at home.

It is critically important to increase support for carers caring for someone with a life-limiting illness at home (especially in the last three months of life). The current system of MyAgedCare fails to provide timely access to community support packages (eg: it sometimes takes four-six weeks for ACAT to conduct an assessment to approve someone for a Level 4 package and following that it may be 10-12 months before it can be allocated).

Inadequate carer support often results in premature hospitalisation. It would be beneficial if specialist palliative care services could directly tap into a Level 4 package (or other similar packages) for palliative patients registered with the service, without waiting for MyAgedCare approval.

Finally it is important to recognise the need for adequately funded bereavement services.

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

All the challenges in metropolitan areas are amplified in rural, remote and regional Queensland – there are issues around staffing, adequate skill mix, access to after-hours care, access to inpatient palliative care beds and access to GP services who are trained and supported in palliative care service provision.

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

The key principle of delivering palliative and end of life care is it should be person-centred and take into consideration the cultural needs of patients. One of the major challenges in Queensland is remoteness and access. For example, for communities in Cape York, the closest palliative care services are in Cairns, some 1000kms away. For people living in the Northern Peninsula Area's five communities who have a life-limiting illness, accessing end of life care often means leaving the community, family and country to travel to Cairns.

With some of the highest levels of chronic disease in the country and an average life expectancy of 58 years, there's considerable need for high-quality and culturally appropriate end of life care across the Cape York and Torres Strait regions. From our experience, following are some of the key factors to take into consideration at service level:

- Involving metropolitan and rurally based Aboriginal and Torres Strait Islander representatives in the design and delivery end of life services is critical. The development of a palliative care model, signed off by the communities and which meets their unique needs is important at community level
- Speaking in plain language (avoiding using only clinical terminology) to the patient/resident and their family members when explaining care options and

procedures. For example, the word “palliation” may not be familiar to community members and their families

- The appointment of an Aboriginal Health Worker to coordinate training and service integration on the ground.
- Aboriginal and Torres Strait Islander communities should feel welcomed and trust community programs and inpatient facilities.
- There needs to be recognition of the significance of dying and how that is approached differently in different cultures *(See case study below)*
- End of life and palliation episodes for Aboriginal and Torres Strait Islander communities may be times of sombre silence, or – more likely in the Torres Strait Islander context – times of talking, singing and laughing with, or around, the patient/resident and an inter-generational audience. The great wailing is likely to occur after passing, therefore; ideally care spaces should accommodate this likelihood and allow also for the sleeping in of family members.
- Design and layout of the facility is central to patient care so family and community members have a space where they are able to express their emotions without the concern they are upsetting other nearby patients. Other practicalities like access to a fridge and the ability to serve the patient/resident traditional foods if possible, also needs to be considered. Further, having access to nature in some capacity is also ideal.
- Understanding that “dying” is not necessarily seen culturally as an event in one moment. There is a lead up period and post-passing “sorry time”, so support for the patient, family and community members during the period, not just on the day of passing, is a critical cultural consideration, as there is an impact on family and community that just doesn’t occur in the passing stage. Therefore service provision needs to factor in this approach.
- Support for family and community members to travel to visit and support the patient in palliative care is critical, particularly when patients are not able to pass away on country.
- Access to Aboriginal and Torres Strait health professionals and support staff so patients and their families can feel culturally safe, welcomed and empowered both in home care and/or in a facility
- Training of GPs, locums, and Queensland Health employees in how the service works, to improve integration and cultural awareness.

Case study – SVHA supports Northern Peninsula Area palliative care services

In 2017 St Vincent's Health Australia committed $450,000 to bring culturally appropriate palliative care services to five Aboriginal and Torres Strait Islander communities in the Northern Peninsula Area (NPA) of Cape York as part of a Memorandum of Understanding (MOU) with Northern Peninsula Area Family and Community Services (NPAFACS) and Apunipima Cape York Health Council (Apunipima).

People living in remote Cape York communities – in particular the five Aboriginal and Torres Strait Islander communities of Bamaga, Seisia, Injinoo, Umagico and New Mapoon – experience some of the highest levels of chronic disease and poorest health outcomes in Australia and yet didn't have access to local palliative care. The nearest palliative care was more than 1000 kms away in Cairns.

St Vincent's Health Australia responded to a need, raised by NPAFACS through Apunipima, for expert guidance to develop a high-quality, culturally appropriate palliative care service tailored and accessible to the communities of the Cape. SVHA signed an MOU which outlines SVHA's commitment over five years to achieve in partnership with NPAFACS, Apunipima and the communities of the NPA, including:

- *Participation in the Commonwealth Government's palliative care education program (Program of Experience in the Palliative Approach or PEPA) which includes capacity for palliative care specialists to visit Aboriginal health services to facilitate palliative care learning.*
- *provision of advanced palliative care training for local staff;*
- *community capacity building through ongoing clinical support;*
- *development of a culturally appropriate model of care and a business plan to establish a permanent palliative care service, and;*
- *provision of specialist care and support of palliative care clients via telehealth.*

Central to this work was SVHA clinicians and key staff first listening to the communities about their palliative care needs and what they wanted so the care service model was developed informed by the views of the communities so they can die respectfully, at home, on country and with family.

The project has developed a fully documented Model of Care which has been informed by community consultation and refined through activity-based research.

Twenty seven (27) patients have been supported over the past fourteen months. Sixteen (16) of those patients have been supported away. There at least another thirty (30) patients that the program is expecting to support over the next twelve months.

24. What are the key priorities for the future?

This Inquiry provides the State with an opportunity to evolve and put in place palliative care and end -of-life care support, which will meet the needs of Queenslanders. There need to be KPIs (such as those suggested above) to ensure each HHS provides an equitable and high quality palliative care service for all Queenslanders.

The following are the key priorities for future reform of the current system:

- **Access to direct admission to inpatient palliative care facilities 24/7 -** Consideration should be given to increasing number of palliative care facilities particularly in areas with population growth. To complement expansion in services, funding should also be provided to up skill the local workforce and/or to attract specialist staff, and community based services. Service planning should enable patients to have direct access from the community into a palliative care bed. (without needing to go through emergency 24 hours a day, 7 days per week)

- **Access to specialist palliative care service advice 24/7 -** All patients in need of palliative care should have access to it no matter what time of the day or week. It is important patients have access to skilled assistants in nursing (AINs) or enrolled nurses (ENs) in the last few days of life. Providing this extra in house support of between 6-24 hours per day for the last few days of life would make an enormous difference to the support and ability of those patients who choose to die at home to actually stay at home in the last few days of life.

- **A need to increase capacity of specialist palliative care service support to residential aged care facilities -** Specialist palliative care 'rounds' to patients in residential aged care facilities can help reduce hospital admissions at the end of life. There is a current gap for specialist palliative care services to provide medical and nursing support and education. There is large variation across Queensland as to what is provided from community specialist palliative care services to Residential Aged Care Facilities (RACFs). It can be challenging for RACF staff to deal with patients who are dying and support is needed. A program to up skill RACF staff and GPs as well as providing consult/share care with GPs is needed. SVHA believes that each RACF should have direct linkages to community specialist care services and that the palliative care providers do regular rounds at the facility.

- **Investment in public education about palliative care -** As detailed there is variable knowledge and understanding about what palliative care is and does. It is important that a comprehensive and detailed public education campaign is undertaken to improve public knowledge. It is especially important that the public understands what palliative care is and what it aims to provide, and how it is distinctly different to euthanasia and VAD.

Voluntary Assisted Dying

25) Should voluntary assisted dying be allowed in Queensland? Why or why not?

SVHA does not support voluntary assisted dying (VAD).

Instead, SVHA recommends the Queensland Government address the currently underfunded palliative care system and increase the availability of services across the state. It would be unacceptable if patients choose to have VAD because they didn't have access to high quality, comprehensive palliative care.

SVHA's position is Queensland must invest more in palliative care and end of life care instead, for the following key reasons.

- **Invest more in palliative care and end of life services**

As outlined in this Submission, Queensland has poor coverage for universally agreed upon end of life care interventions, which are recognised as human rights by the United Nations.[17]

Such care incorporates access to a full range of palliative care services, including adequate pain relief, psychosocial and spiritual care, advanced care directives, and support of the right to withdraw or withhold burdensome treatments. There is inadequate access to palliative care for vulnerable groups, such as Aboriginal and Torres Strait Islander people culturally and linguistically diverse communities, and others living in poverty, but inequity of access and care is also obvious geographically in a decentralised state such as Queensland.

The State should invest further in strengthening the reach and improving the access of all Queenslanders to palliative care and end of life planning first. Our experience of working with patients across our hospitals, and in particular palliative care units is, that when there is absence of adequate end of life care, VAD may be seen as the only viable option. Patients facing end of life choices should never be put in a position where they think the only option available to them is VAD.

Our experience from participating in discussions about the VAD legislative framework in Victoria, is any form of 'safeguard' which purports to protect patients from potentially only considering VAD by informing patients about palliative care, is meaningless if there are no adequate palliative care options.

If this legislation is introduced into Queensland with the current under-resourcing and under-provision of palliative care there is a real risk that patients will be asking for VAD because of inadequate symptom control, or wishing not to be a burden on others or fearing loss of autonomy."[18]

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[17] THE RIGHT TO END-OF-LIFE PALLIATIVE CARE AND A DIGNIFIED DEATH, CONTRIBUTION FROM UN-ECLAC FOR THE EXPERT GROUP MEETING ON "CARE AND OLDER PERSONS: LINKS TO DECENT WORK, MIGRATION AND GENDER", 2017. https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2017/11/ECLAC-contribution.pdf

[18] This is evidenced through 21 years of data captured in Oregon: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/index.aspx

This is important to recognise because the research shows that requests for VAD are not for pain and symptom control, but rather because of a person's ideal or values, and their experience of loss of (or fear of loss) of dignity.

Through this Inquiry, the State of Queensland has an opportunity to invest and put in place a world class palliative care and end of life care system, one that models how patients can secure access to end of life care by supporting innovative service models which are designed to meet the needs of culturally diverse communities and patients living in regional, rural and remote areas.

- **Combat suicide rate**

SVHA argues the contradiction of society's efforts to address the problem of suicide on one hand while potentially introducing legislation that affords individuals an opportunity to voluntarily choose dying.

Some parts of Queensland have the highest suicide rates in the world, and our society rightly laments when we see people, old and young, who see no hope in their current life situation and for whom suicide appears as the only option. In such cases, our society rightly avoids blame towards the victim, and seeks instead to address the various tragic circumstances, which led to this to prevent others from doing the same. Often this involves addressing lack of adequate support networks, socio-cultural factors, and any health conditions, which include a high risk of suicide.

In such a context, establishing a group of select people for whom suicide is not only tolerated but valued, and indeed praised (as recent media coverage surrounding those who have travelled to Switzerland to end their lives reveals) sends a deeply confusing and contradictory message to those who we are trying to help, and undermines our society's attempts to say that suicide is never an answer.

SVHA argues that addressing the problems which give rise to a desire for VAD can be achieved through the means our society already commits to responding to the tragedy of suicide by addressing lack of adequate support networks, socio-cultural factors and health needs and concerns of individuals.

- **Impact on health professional's traditions and morale**

In a similar way, legislating for VAD, when it involves health practitioners, undermines fundamental commitments of healthcare professionals, which are upheld in the Hippocratic tradition of medicine.

These include commitments to cure where possible, to care always and never intentionally to inflict death. In addition, this tradition of care trains clinicians to provide effective pain management and to respect patients' decisions (or, if they are not competent, their substitute decision-maker's decisions) to forgo treatments that are too burdensome or medically futile: in doing so, it ensures that clinicians act in accordance with the needs and preferences of the patients. This said, this tradition of care – which is the foundation of

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modern medicine – never accepts that intentionally inflicting death on patients nor assisting them to take their own lives are part of healthcare. Making them as such undermines healthcare.

These statements are consistent with the World Health Organisation and the Australian Medical Association's positions on assistance in suicide and euthanasia.[19]

Legislation such as VAD gives rise to unprecedented ethical issues and potential distress for caregiving staff and families. Cases in other jurisdictions bring this to the fore.

There are examples from facilities in Canada which has in place 'Medical Assistance in Dying' (MAiD) legislation, which illustrate some of the ethical issues and distress such legislation can give rise to:

(1)

- A resident from an aged care facility accesses MAiD, but instructs caregiving staff not to inform his family nor other residents;
- The staff farewell the resident from their facility, knowing that he is leaving to be euthanized, but cannot disclose this to family or other residents;
- When the man is deceased, the staff need to explain this both to family and to other residents, creating a situation *not unlike* other suicides or unexpected deaths, but with the added emotional complexity of 'knowing all along';

(2)

- A long term in-patient at a sub-acute palliative care service has been through the process and has been approved for MAiD;
- The patient has selected a day on which the MAiD procedure will be completed;
- Their condition is such that they require aggressive medical treatment to live until their preferred MAiD day. If the patient chose not to undertake such treatment, they would die naturally and with adequate pain management before this time;
- The patient requests such treatment from medical staff, who provide it whilst knowing that its purpose is to prolong life until euthanasia can be enacted;

Even setting aside these somewhat extreme cases, issues surrounding how staff deal with cases in which someone dies in a way that would once have been tragic (i.e. suicide) and is now normalised (through a 'voluntary assisted dying' regime) gives rise to distress and grief which are not solved through legislative instruments.

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[19] https://www.wma.net/policies-post/wma-resolution-on-euthanasia/
https://ama.com.au/position-statement/euthanasia-and-physician-assisted-suicide-2016

- **Cost of VAD**

SVHA also argues that legislating for, and rolling-out, a regime such as VAD is a costly exercise, both in terms of the funding expended on the regime and also the burden that health services take on in responding to the legislation. It is unconscionable to spend valuable health dollars on introducing VAD when many Queenslander's do not have adequate access to palliative care.

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

'VAD' should be defined in very clear terms so as to distinguish it from interventions which are uncontroversial and upheld as universal human rights, but which are often confused with VAD regimes, including fully adequate pain relief and the withdrawal or refusal of overly burdensome treatments. It is irresponsible to push through policy which clouds its outcomes by using euphemisms such as 'voluntary assisted dying', which distract from what is actually being legislated.

The definition of 'VAD' should be limited to the direct and intentional administration of a substance that has the goal of causing a patient's death, or the prescription of a substance for self-administration with the same goal. The definition should use the language of the World Health Organisation and the Australian Medical Association which refer to these interventions as 'euthanasia' and 'physician assisted suicide'.

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

SVHA does not support VAD being introduced. (See responses to Questions 25 and 28) In the event VAD is introduced in the State we advocate consideration be given to:

- Clarity about the referral process
- The right of health care providers and individual health practitioners to exclude themselves from participating in VAD process and
- The need for guidelines around what to do in case of an adverse outcome of VAD – for example – the patient does not die, or patient suffers a brain injury

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

We note that our response to this question is not to be understood as tacit support for the introduction of a VAD regime. That said, should the state of Queensland choose to introduce such a scheme, we argue that the following need to be considered to mitigate some of its harmful effect:

- The state should guarantee that any person who is seeking VAD is also afforded the opportunity for meaningful exploration of palliative care options, which would include the capacity to *access* and *receive* such options in their preferred location.

- Research demonstrates that the desire for a hastened death often dissipates once palliative interventions take effect, hence this is an important safeguard against the coercion noted above
- The process should include rigorous assessments for various forms of coercion: 1) clear and obvious coercion (such as a person of influence prompting and encouraging the decision, which is against the person requesting's will) and 2) tacit coercion (such as a person feeling like a burden because of socio-cultural norms about aging and disability which give them this impression). We note that both forms of coercion cannot be adequately identified outside of meaningful therapeutic relationships
- That the lethal substance used to cause death be strictly regulated to ensure that it does not present a danger to other people
- That it should be made clear that VAD is not part of palliative care practice and that VAD will not be performed in palliative care facilities and
- That individual health practitioners and facilities/services must consent to participating in the practice of VAD, and there is no obligation to do so.

Questions 29 to 38

SVHA does not support the introduction of VAD therefore we will refrain from responding to questions 29 to 38.