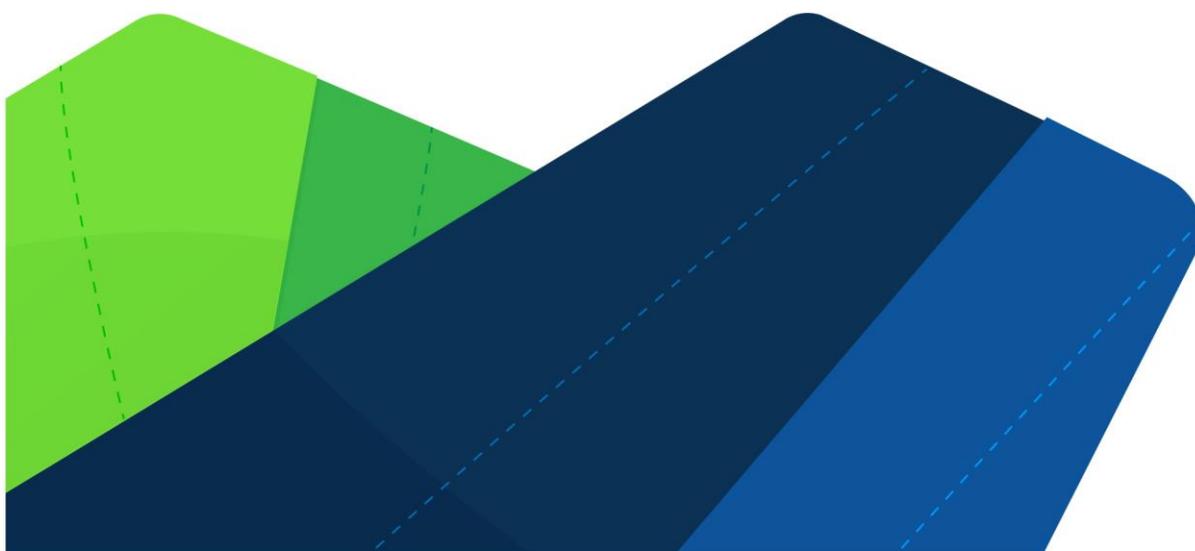


# Queensland Health Palliative Care Services Review – Key Findings

March 2019



## Queensland Health Palliative Care Services Review – Key Findings

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## Introduction

The health system in Queensland delivers a broad range of essential acute and sub-acute services in both hospital and community settings. As Queenslanders, we are living longer, enjoying the benefits of a world class health system and continual advancements in technology, medicine and diagnosis.

The Queensland Health Palliative Care Services Review (the Review), conducted by the Queensland Department of Health (the Department), sought to identify current and future palliative care service needs. The learnings of the Review will be used to implement a more person-centred, accessible and integrated system of palliative care in Queensland.

Global megatrends are shaping the world, challenging the way governments design and deliver social services. Changing demographics, technological advancements and rising demand for personalised services that meet unique needs are creating both opportunities and challenges for policy makers and service delivery teams.

The way palliative care services are delivered across Queensland varies according to geographical location, local needs and resource availability. These services, like many others, are increasingly impacted by the growing and ageing population, rising prevalence of chronic disease, changing availability and utilisation of new technologies and shifting public and consumer expectations.

The Review aimed to respond to these trends and issues by undertaking:

- an environmental scan to determine what palliative care is, who is responsible for delivering palliative care and what policies and legislation exist to drive the delivery of a quality palliative care system;
- an interjurisdictional analysis that identifies initiatives being undertaken in Queensland and other jurisdictions that impact delivery of palliative care services;
- the commissioning of an independent literature review that considers best practice palliative care, demand for palliative care and innovations in delivering quality palliative care services;
- an analysis of the current funding and delivery of palliative care services in Queensland;
- an analysis of the demand trends impacting the delivery of palliative care services in Queensland; and

- a public and stakeholder consultation process to gather information about perceived barriers to the delivery of quality palliative care services in Queensland and suggested improvements.

It is intended that the findings of the Review will inform a system-wide strategic approach for future palliative care service arrangements in Queensland.

## The Queensland Health Palliative Care Services Review

### Environmental Scan

#### What is palliative care?

The need for palliative care services can occur at any age and palliative care is provided in a range of settings, including paediatric services, general practices, residential aged care facilities (RACFs), acute hospitals and generalist community services. Palliative care is available to all those affected by life-limiting illnesses and seeks to improve the quality of life of individuals, carers, and family and friends supporting them, as well as reducing the physical and emotional distress of dying.

Palliative Care Australia defines palliative care as, “person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life”. It is care “that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness”.<sup>1</sup>

The World Health Organization<sup>2</sup> definition is that palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;

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<sup>1</sup> Palliative Care Australia, 2018, What is Palliative Care, Available at <https://palliativecare.org.au/what-is-palliative-care>. Accessed 22 February 2019.

<sup>2</sup> World Health Organization, 2018. WHO Definition of Palliative Care. Available at <http://www.who.int/cancer/palliative/definition/en/>. Accessed 1 March 2018.

- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Australian Health Ministers have endorsed the Australian Government's *National Palliative Care Strategy 2018*, which notes that "palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual".<sup>3</sup>

### Responsibility for palliative care

The policy, funding and service delivery contexts for aged care, end-of-life care and palliative care services are complex. Services are delivered by public and private providers, across primary health care, community health care and acute hospital settings, and funded through both the State and Australian Governments. Under the *National Health Reform Agreement*, the states are the system managers of the public hospital system, and the Australian Government has full funding and program responsibility for aged care and lead responsibility for General Practitioner (GP) and primary health care.

Therefore, Australian Government has responsibility for funding palliative care through general practice and RACFs. The Australian Government and Queensland Government jointly fund palliative care through public hospital funding, with the Queensland Government being responsible for the delivery of specialist public palliative care services, including community palliative care, inpatient and outpatient services, and providing support to primary health care providers. The challenge for both governments is to deliver person-centred models of care that overcome the policy and funding barriers and result in good patient outcomes.

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<sup>3</sup> Australian Government, 2018. *National Palliative Care Strategy 2018*. Canberra.

The Department is the system manager of the health system in Queensland and is responsible for ensuring the health budget is allocated to health services in an equitable and transparent manner. Public health services in Queensland are provided through 16 Hospital and Health Services (HHSs) established under the *Hospital and Health Boards Act 2011* as statutory bodies. Under this Act, service agreements are negotiated between the Department and each HHS for the purchase and delivery of health services. HHSs are responsible for planning and delivering health services to meet the needs of their local communities within their allocated budgets. Each HHS may identify different priorities for its community and plan for different services.

*The health of Queenslanders, Report of the Chief Health Officer Queensland 2018* forecasts that by 2026 Queensland's population will increase to 5.7 million, an increase of about 880,000 people.<sup>4</sup> Of those people, one third will be aged 65 or older - an increase of approximately 300,000 older Queenslanders. The State's changing age profile will impact the demand for GP and hospital services, community-based support and residential aged care. As the demand for health services continues to increase, the Department as system manager needs to adapt and respond to maintain system effectiveness and sustainability.

### Key policies and strategies informing palliative care

The delivery of palliative care services across Queensland is guided by several national and state level strategic documents and policies. These include:

- The updated *National Palliative Care Strategy 2018*<sup>3</sup> was released in February 2019, and has been endorsed by all Australian and state and territory Health Ministers. The 2018 Strategy is based on an evaluation and review of the *National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End of Life*.<sup>5</sup>
- The *National Palliative Care Service Development Guidelines*<sup>6</sup> and *National Palliative Care Standards*<sup>7</sup> - updated by Palliative Care Australia in February 2018 - sets out Palliative Care Australia's expectations regarding the range of palliative care services that should be available, and the workforce and system capabilities required to deliver an effective network of palliative care services.

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<sup>4</sup> Queensland Health. The health of Queenslanders 2018. Report of the Chief Health Officer Queensland. Queensland Government. Brisbane 2018.

<sup>5</sup> Commonwealth of Australia, 2010. National Palliative Care Strategy 2010 – Supporting Australians to Live Well at the End of Life. Canberra.

<sup>6</sup> Palliative Care Australia, 2018. National Palliative Care Service Development Guidelines. Canberra.

<sup>7</sup> Palliative Care Australia, 2018. National Palliative Care Standards. Canberra.

- The Australian Productivity Commission's 2018 report, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*<sup>8</sup>, includes information about end-of-life care services. Key recommendations in the report include:
  - State and territory governments should increase the availability of community-based palliative care so that people with a preference to die at home can access support to do so.
  - End-of-life care should be core business for RACFs, and the quality of end-of-life care in residential aged care should align with the quality of that available to other Australians.

The Australian Productivity Commission identified that investment in community-based palliative care is likely to be cost-effective for government, given home-based care can cost less than its hospital-based alternative. However, it is important to note that palliative care services involve a range of options depending on patients' needs. Services in the community are not always able to be a substitute for hospital-based care and not all people choose to receive palliative care in a community-based setting.

These strategies, guidelines and reports help to set the framework for palliative care services delivery in Queensland.

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<sup>8</sup> Productivity Commission 2017, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*, Report No. 85, Canberra.

## Interjurisdictional Analysis

### Queensland

There have been several initiatives in Queensland in recent years to improve palliative care. In 2012, the Queensland Parliament's Health and Community Services Committee undertook an inquiry into Queensland's chronic, frail and palliative care services at the request of the Legislative Assembly. In its report, *Palliative and community care in Queensland: toward person-centred care*<sup>9</sup>, the Committee recommended the development of a statewide palliative care strategy to improve the health system's capacity to provide high quality palliative care.

The *Statewide strategy for end-of-life care 2015*<sup>10</sup> was subsequently developed by the Department in partnership with the Palliative Care Sub-Network of the Statewide General Medicine Clinical Network, and was endorsed by the then Minister for Health and Minister for Ambulance Services in May 2015.

The *Care at end-of-life: Implementation Plan 2015–2025*<sup>11</sup> was developed to implement the Strategy. It includes actions to: increase public awareness of, and access to, advance care planning, identify and share best practice, and develop standardised assessment and management tools. Actions of particular relevance to a review of palliative care services include: undertaking a needs analysis to inform service planning and considering viable service funding mechanisms, including those for home based care at the end-of-life.

Charters have been developed for the care of patients at the end-of-life, to provide a platform for patients and their families and carers to openly discuss their wishes for care at the end-of-life with healthcare workers. These charters are called: *A charter for care of adult patients at the end-of-life*<sup>12</sup> and *A charter for children and young people affected by a life-limiting condition*.<sup>13</sup>

During October and November 2017, Queensland Health launched the care at the end-of-life state-wide public awareness campaign, with the call to action: "Start your conversation". The campaign targeted Queenslanders aged 45 years and over, with a focus on those who are experienced with the healthcare system and services, and multidisciplinary healthcare

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<sup>9</sup> Health and Community Services Committee, 2013. Palliative and community care in Queensland: towards person-centred care Report No. 22. Brisbane.

<sup>10</sup> Queensland Health, 2015. Statewide strategy for end-of-life care 2015. Brisbane.

<sup>11</sup> Queensland Health. Care and end-of-life: Implementation Plan 2015-2025. Brisbane.

<sup>12</sup> Queensland Clinical Senate, *A charter for care of adult patients at the end-of-life*, Available at [http://hcq.org.au/wp-content/uploads/2015/09/QCS-HCQ-Patient-Charter\\_v1.0.pdf](http://hcq.org.au/wp-content/uploads/2015/09/QCS-HCQ-Patient-Charter_v1.0.pdf).

<sup>13</sup> Queensland Clinical Senate, *A charter for care of children and young people affected by a life-limiting condition*, Available at [https://www.health.qld.gov.au/\\_data/assets/pdf\\_file/0030/636087/qcs-children-charter.pdf](https://www.health.qld.gov.au/_data/assets/pdf_file/0030/636087/qcs-children-charter.pdf).

workers (medical, nursing, allied health, administrative, management) who are involved in the delivery of care at the end-of-life. The campaign aimed to:

- build awareness and a common language about care at the end-of-life, and help 'normalise' public discussion about death and dying;
- support and promote care at the end-of-life and advance care planning tools and services; and
- motivate Queenslanders to plan their end-of-life care.

The Department, as system manager, has provided funding to HHSs to enable innovation in care at the end-of-life. Since 2016-17, funding has been provided for seven projects across Queensland including, but not limited to, topics such as: improving care pathways in the emergency department, better understanding community and consumer perspectives, supporting care plans for dying children, improving end-of-life conversations, supporting discharge from hospital to enable dying at home and building capacity outside of specialist palliative care settings.

Also building on the Queensland Parliament's 2012 inquiry recommendations, Queensland's only children's hospice, Hummingbird House, opened in 2016 and receives Queensland and Australian Government funding. Hummingbird House is a state-wide service and provides hospice-based and in-home palliative care for children.

It is intended that the outcomes from the Review will help to continue to enhance the palliative care system in Queensland.

## Other jurisdictions

Desktop research conducted by the Department suggests that Australia's states and territories have relatively similar models of palliative care delivery, and acknowledge similar values that should be prioritised, such as patient-centred, integrated and holistic care, and access to appropriate, high quality and preferred care options.

Australia's states and territories also provide palliative care services across similar settings. In metropolitan areas of Australia, palliative care is generally provided by public and private hospitals, non-government organisations (NGOs), hospices, RACFs, GPs and in-home services. Consistently, a large proportion of palliative care is delivered in hospital settings, which can have varying availability of palliative care, from little to no publicly-funded dedicated beds and staff, to extensive palliative care units, and specialist consultancy services. A consistent feature of palliative care service delivery across the states and territories is that there are often reported to be few paediatric hospices available. Rural models of care

generally include a palliative care service provider such as a hospital or a hospice located in a regional centre of the state or territory, which may provide out-patient or telehealth services.

Examples of key recent developments announced or implemented to improve palliative care service delivery in other Australian states and territories include:

- **New South Wales:** New South Wales Health is developing a framework for palliative and end-of-life care services. Issues raised during the consultation process for the framework are being addressed by the New South Wales Government through increased investment in palliative care services. In June 2017, the New South Wales Government announced an additional \$100 million dollars funding over four years for palliative care, to support people suffering from terminal illness. This was in addition to the estimated \$210 million spent annually on palliative care services. The 2017-18 budget included \$17.4 million of the additional funds, providing palliative care training for 300 nurses and allied health staff, 300 scholarships for rural and regional staff to enhance palliative care skills, an additional nine palliative care specialists in rural and regional areas, two specialist positions to provide relief to other specialists in rural and regional areas, an additional 30 palliative care nurses providing care in hospitals, homes and nursing homes and improving medication management for palliative care patients through community pharmacy initiatives.
- **Victoria:** In 2018, the Victorian Minister for Health commissioned a review of the palliative care funding model to seek advice from an expert panel on the best approach to palliative care funding to meet community needs into the future. In 2017-18 the Victorian Government provided \$142.5 million in funding for palliative care services. On 30 October 2018, a commitment of an extra \$23.4 million for 2018-19 was announced to increase palliative care beds and boost access to home-based palliative care in metropolitan areas. This investment was in addition to \$62 million the Victorian Government provided in November 2017 to expand rural and regional home-based palliative care, establish a state-wide 24-hour expert advice service and deliver grants for community-based end of life ancillary support services.
- **Western Australia:** In 2018, the Western Australian Department of Health released the *Western Australian End-of-Life and Palliative Care Strategy 2018-2028*<sup>14</sup> to provide strategic state-wide policy direction and outline the vision, values and priorities for end-of-life and palliative care in Western Australia to 2028.

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<sup>14</sup> Western Australian Department of Health, 2018. Western Australian End-of-Life and Palliative Care Strategy 2018-2028. Perth.

- Australian Capital Territory: Australian Capital Territory Health is currently conducting a *Territory Wide Palliative Care Service Project* to provide direction for the delivery of care in line with the recently revised national *Palliative Care Standards*<sup>7</sup> developed by Palliative Care Australia.
- Tasmania: In 2017, the Tasmanian Minister for Health released the Tasmanian Government's strategic vision and priority framework for palliative care in Tasmania, *Compassionate Communities: A Tasmanian Palliative Care Policy Framework 2017-21*<sup>15</sup>, to improve access to community-based palliative care for people in Tasmania. On 24 March 2017, the Tasmanian Government announced the provision of \$81,314 in additional Better Access to Palliative Care project funding, which supported the service to continue until the end of 2017.

The jurisdictional analysis revealed that several other states have recently made significant policy and funding investment to improve their palliative care systems.

## Literature Review - Palliative Care Services

In October 2018, the Department commissioned the Queensland University of Technology School of Nursing to undertake an independent literature review to inform the Review. *The Palliative Care Services Review: Commissioned External Literature Review – Final Report (unpublished)* (the Literature Review) was finalised in January 2019.

Key areas of information provided about palliative care in the findings of the Literature Review are:

- demand and unmet need;
- best practice;
- effectiveness of palliative care services;
- funding models of palliative care services in Australia;
- comparison of palliative care service models;
- key priorities; and
- innovations in palliative care service provision.

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<sup>15</sup> Tasmanian Government, 2017. *Compassionate Communities: A Tasmanian Palliative Care Policy Framework 2017-21*. Hobart.

## Palliative Care in Queensland

There are a range of specialist palliative care services available within Queensland offering advice, information, referral and support for a person with a life-threatening illness, their family, friends, carers and health professionals.

There are several pathways by which people can receive palliative care. Palliative care can be delivered in the home, community or in a hospital setting. Providers of palliative care include GPs, public and private hospitals, hospices, non-government and private sector organisations, RACFs and families and carers. Depending on the type of service, admission can be arranged through GP, specialist or nurse referral, treating clinic or hospital referral, referral from community organisations, or direct requests from patients, carers or family members.

## Hospital and Health Services

Queensland's HHSs provide specialist palliative care services, including in-patient care in a designated bed, consultation liaison and outpatient services in the acute hospital setting, and specialist palliative care advice and support to home and community-based care.

## Specialist palliative care

A 'separation' is used to describe an episode of care for an admitted patient, which can be a total hospital stay (from admission to discharge, transfer or death), or a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute to rehabilitation).<sup>16</sup> Separation also means the process by which an admitted patient completes an episode of care either by being discharged, dying, transferring to another hospital or changing type of care.<sup>16</sup> An episode of care refers to a period of health care with a defined start and end.<sup>17</sup> Specialist palliative care separations can occur in both a hospital and home setting. Bed days refer to the number of days of stay for an admitted patient who underwent a separation.

Of the total 11,438 palliative care separations across Queensland in 2017-18, the average length of stay was nine days.<sup>18</sup> Over three quarters of these separations were delivered by

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<sup>16</sup> Australian Institute of Health and Welfare, Glossary, Accessed on 24 January 2018, Available at <https://www.aihw.gov.au/reports-data/health-welfare-services/hospitals/glossary>.

<sup>17</sup> Australian Institute of Health and Welfare, Episode of care definitional attributes, Accessed on 24 January 2019, Available at <https://meteor.aihw.gov.au/content/index.phtml/itemId/268978>.

<sup>18</sup> Analysis of Palliative Care Demand prepared by Health Service Research, Analysis and Modelling Unit, System Planning Branch, Strategy, Policy and Planning Division, December 2018.

HHSs (Table 1). In 2017-18, approximately 100,000 days of specialist palliative care were provided in Queensland hospitals and 64 percent of these days were spent in public hospitals.

*Table 1. Specialist palliative care for all ages, all facilities, all funding types by residence, 2017-18.*

Place of residence	Separations 2017-18	Bed days 2017-18
Cairns and Hinterland	644	6,274
Central Queensland	364	2,565
Central West	16	72
Darling Downs	862	7,597
Gold Coast	1,014	8,822
Mackay	162	1,209
Metro North	2,175	22,131
Metro South	3,008	28,742
North West	58	820
South West	54	516
Sunshine Coast	1,020	5,562
Torres and Cape	36	479
Townsville	595	5,560
West Moreton	708	6,062
Wide Bay	662	4,978
Interstate/overseas/Unknown	52	378
Not stated	8	65
<b>Total in public and private facilities</b>	<b>11,438</b>	<b>101,832</b>
<b>Total in public facilities (includes public and privately funded care)</b>	<b>8,897 or 78% of all separations</b>	<b>65,293 or 64% of bed days</b>

Source: Analysis of Palliative Care Demand prepared by Health Service Research, Analysis and Modelling Unit, System Planning Branch, Strategy, Policy and Planning Division, December 2018.

## Paediatric palliative care

In 2017-18, Queensland Children's Hospital delivered 128 episodes of specialist paediatric palliative care to 73 young Queenslanders (Table 2). Additionally, three children received specialist paediatric care at other public hospitals, however, due to confidentiality, these hospitals cannot be identified.

*Table 2. Episodes of admitted patient care for care type of 'Palliative', 0 - 17 years, public hospitals, Queensland, 2017-2018.*

Facility	Episodes	Distinct patients
<b>Queensland Children's Hospital</b>	128	73
<b>Other Hospitals</b>	3	3
<b>Queensland</b>	131	76

Source: Queensland Hospital Admitted Patient Data Collection (QHAPDC), Queensland Health  
Produced by: Statistical Reporting and Coordination, SPPD, 18 January 2019.

Hummingbird House works closely with the Children's Health Queensland Paediatric Palliative Care Service, a statewide service which began operation in 2008 and provides a flexible and responsive model of service delivery centred around the patient and family and tailored to their specific needs and circumstances. The service receives approximately 100 referrals per year with approximately 60 deaths per year and works closely with families to ensure end-of-life care is provided in the location preferred by the family and clinically appropriate. This care can be in hospital, at home or at Hummingbird House.

## Palliative care in prisons, detention centres and forensic mental health units

Some HHSs, such as West Moreton, have responsibility for providing health services to prisons, detention centres and forensic mental health units. West Moreton HHS has reported an increasing population of prisoners diagnosed with a life-limiting illness. The care needs of these prisoners are like those in the community but the current access to services is generally at the primary care level.

The Queensland Coroner recently undertook an inquest into the death of a prisoner in Queensland.<sup>19</sup> The prisoner had a life-limiting illness and died in prison. The Coroner recommended that the Queensland Government review the current model for the provision of

<sup>19</sup> Queensland Courts, Coroners Court of Queensland Findings of Inquest, Inquest into the death of Jay Maree Harmer, Available at [https://www.courts.qld.gov.au/\\_data/assets/pdf\\_file/0009/578916/cif-harmer-jm-20180810.pdf](https://www.courts.qld.gov.au/_data/assets/pdf_file/0009/578916/cif-harmer-jm-20180810.pdf). Accessed 22 February 2019.

palliative care for prisoners with a focus on considering where and how care is delivered as well as post release supported accommodation options for prisoners on parole.

## Telehealth

Like many other health services, there are differences in the models of care, the variety of care options and the way palliative care services are delivered in rural and remote areas compared to metropolitan service settings.

Telehealth and visiting medical specialist services are just some examples of how services are delivered differently in regional, rural and remote areas to ensure access to palliative care services.

Telehealth palliative care services are an emerging model, enabling an innovative and patient-focused service for palliative care patients to stay in their own homes while receiving specialist consultation via videoconference.

Typically, the model involves the patient being visited by a palliative care specialist nurse, who conducts all the required assessments such as blood pressure, pulse and pain assessments. The nurse brings a Queensland Health iPad, and the consultant dials into this iPad. The model supports a reduction in travel by clinicians and patients and facilitates a more efficient use of clinicians' time.

There are significant benefits to consumers, in addition to reduced travel times, including more opportunities to see their consultants and for their families to be involved during consultations.

In 2017-18, there were 1,872 non-admitted patient (outpatient) telehealth service events for palliative care reported across 13 HHSs, 58 percent more than in 2016-17.

There were also 348 telehealth consultations for palliative care for admitted patients reported across Mackay, Sunshine Coast, Townsville, and West Moreton HHSs. These services were generally provided and received within a hospital or other health service setting.

## Private facilities

The Department does not collect or hold information about privately-funded palliative care. It does collect information on publicly-funded palliative care services in both public and private facilities (i.e., public patients in private facilities).

Both Medicare and private health insurance offer palliative care options for public and private hospitals. If a person accesses palliative care in a private hospital, Medicare and private health insurance rebates apply, with the Australian Government paying 75 per cent of the Medicare Benefits Schedule (MBS) fee for private hospital palliative care patients, and the remaining 25

percent, as well as any gap, required to be paid by the patient or their health insurance provider. MBS coverage for palliative care patients includes rebates available for GP attendance services, creation of GP management plans, team care arrangements and multidisciplinary care plans.

## Non-government organisations

The Department has contracts with seven NGOs that deliver clinical palliative care services within the community. These NGOs are:

- Cittamani Hospice Service;
- Ipswich Hospice Care Inc;
- Hopewell Hospice Services (now part of Wesley Mission Queensland);
- Karuna Hospice Service Ltd;
- Little Haven Cooloola Sunshine Coast Palliative Care Association Inc;
- St Vincent's Private Hospital; and
- Toowoomba Hospice Association Inc.

In addition, the Department jointly provides funding, with the Australian Government, to Hummingbird House (Wesley Mission Queensland) under a separate contractual arrangement.

All NGOs deliver their services in different ways with some providing home and community-based care only, others providing hospice bed-based care only and others providing both. Even within the NGOs providing just home and community-based care, there is wide variation in the services that are reported to be provided to clients. While all these organisations provide palliative care nursing, some also focus on respite, others psychosocial support and another offers medical support and support over the telephone. Palliative care can include a range of options depending on the client's needs, therefore, it can be difficult to compare outputs across organisations. Departmental funding is also provided to NGOs for non-clinical palliative care services as follows:

- Palliative Care Queensland – for information and community awareness services
- St Vincent's Private Hospital – Training Fellowship Program
- Cancer Council Queensland – 24 hours State-wide palliative care helpline (PalAssist) and nurse counselling pilot.

## General Practitioners

The Australian Government is responsible for palliative care service delivery by the primary health care sector. GPs provide home-based and community palliative care services and are integral to helping consumers if they have a preference to die at home, including residential aged care homes.

GPs can provide palliative care at their clinics (face-to-face or telehealth), in people's own homes (RACFs and privately-owned homes) and some GPs provide palliative care support to patients in hospices.

A GP's role will vary depending on the needs of the patient and their carer or family. Responsibilities may include:

- identifying patients' end-of-life needs;
- advance care planning;
- referrals to specialist palliative care services;
- holistic symptom management and optimising quality of life, including prescription of pain management medications;
- supporting a person to die in their place of choice;
- addressing the needs of family and significant others;
- providing grief and bereavement care or referring to specialists as needed;
- supporting care workers in the community, including staff in RACF;
- commissioning services to support the person;
- referring patients for Aged Care Assessment Team assessments as required; and
- coordinating with other health care providers such as specialists.

Each RACF resident usually has a nominated GP who can deliver or refer to palliative care services in line with the general community. Residents are eligible to receive a limited number of funded palliative care services in their facility through the Aged Care Funding Instrument (ACFI). In addition, many HHSs provide specialist in-reach services to support the facilities or GPs to provide comprehensive palliative care services to residents.

## Funding

The Department provides funding to HHSs and NGOs for the provision of palliative care services in a range of settings, including in hospital, hospice, community, residential aged care and home settings.

### Hospital and Health Services

Healthcare purchasing negotiations occur annually with HHSs to provide sub-acute and acute health services. This process results in 16 HHS annual service agreements. These agreements outline the services that the Department will purchase from each HHS and how much will be paid for the provision of these services.

Table 3 below displays the annual funding that the Department allocated to HHSs for palliative care services from 2013-14 to 2018-19.

*Table 3. Activity-based funding for palliative care services (\$,000).*

2013/14	2014-15	2015-16	2016-17	2017-18	2018-19
(Actuals)	(Actuals)	(Actuals)	(Actuals)	(Actuals)	(Budget)
\$99,362	\$98,756	\$101,352	\$103,696	\$101,046	\$105,000

Source: Healthcare Purchasing and System Performance Division, Queensland Health, December 2018.

In 2017-18, the total amount spent across HHSs for palliative care services, including admitted patient allocation, non-admitted patients and community palliative care services to admitted patients, was approximately \$101,046 million. The overall funding for HHSs has increased from approximately \$101 million in 2017-18 to an anticipated \$105 million for 2018-19.

### Non-government organisations

In 2018-19, the Department will provide over \$9 million for NGOs for palliative care services. Most of this funding is used by these NGOs to provide clinical community-based palliative care services, however, some funding is used for education and information services such as the PalAssist online and telephone service.

NGOs also receive income/revenue from sources other than the Department's block funding. These revenue sources vary depending on the organisation and the business model that they adopt to deliver their services. Some NGOs receive small proportions of their revenue as payments for scripted services under panel arrangements from HHSs directly to deliver palliative care services in the local area.

NGOs may also receive revenue/income from other sources including:

- donations and bequests;
- fundraising activities/special event income;
- private health insurance services;
- other revenue from provision of services; and
- grants – from a range of sources including the Australian Government, other government and non-government sources.

NGOs have historically had strong streams of income from fundraising. However, NGOs have reported that fundraising income is reducing. This may be due to a range of factors, including a tighter economic environment and stronger competition for community fundraising and donations in their local area. NGOs are expressing a need to move away from their current level of dependence on fundraising activities as a key area of revenue in their business model.

NGOs use different strategies to manage increasing demand. Some organisations control demand by reducing the length of time that care is provided to a client (e.g., from months to weeks) rather than reducing the number of clients that they support. Others do not have a strategy and continue to accept all referrals, which can lead to difficulties in meeting service demand.

NGOs regularly seek additional base funding from the Department to meet increased demand and to increase the long-term sustainability of their service.

## Demand for Palliative Care in Queensland

While Queensland has made strong gains to reduce the rate of premature deaths and deaths for lifestyle-related conditions, our ageing population will live longer with illness and disability, increasing demand for healthcare services.

As acknowledged in the Literature Review, it is important to note that there is no consensus regarding the patient population who would benefit from palliative care services. In particular, current methods for estimating palliative care demand do not distinguish between need for specialist and non-specialist palliative care services and there is no consensus regarding the patient population in Queensland who would benefit from palliative care services.

It is known that the burden of chronic conditions associated with an ageing population is increasing, including musculoskeletal disorders, nervous system disorders, mental disorders

(including dementia) and substance use disorders, diabetes, vision loss and hearing loss<sup>20</sup>. The prevalence of most of these conditions rises sharply with age, and as people survive into their 70s and 80s and beyond, the amount of time spent with these disorders increases, as does the treatment required.<sup>20</sup>

Of the 29,690 deaths in Queensland in 2016, cancer and cardiovascular disease are the leading broad causes of death, accounting for six in 10 deaths (Table 4). While ranked the fourth leading cause of death in Queensland, across Australia, dementia and Alzheimer disease is the second leading cause of death.<sup>21</sup> The provision of palliative care will need to expand from the traditional focus on cancer to also cater for dementia and other life limiting illnesses which predominantly affect older persons.

*Table 4. Leading causes of death, Queensland, 2016.*

Rank	Persons	
	Cause	Deaths
1	Coronary heart disease	3,809
2	Stroke	2,066
3	Lung cancer	1,741
4	Dementia	1,417
5	COPD	1,372
6	Colorectal cancer	882
7	Diabetes	842
8	Prostate cancer	687
9	Suicide	673
10	Alzheimer disease	602
11	Breast cancer	566
12	Pancreatic cancer	541
13	Influenza and pneumonia	497
	All causes	29,690

Source: Queensland Health. The health of Queenslanders 2018. Report of the Chief Health Officer Queensland. Queensland Government. Brisbane.

Aboriginal and Torres Strait Islander Queenslanders experience a disproportionate burden of disease compared with others. The death rate for Aboriginal and Torres Strait Islander Queenslanders was 49 percent higher than the rate for non-Indigenous Queenslanders after accounting for differences in age between the two populations. There were 884 deaths of Aboriginal and Torres Strait Islander Queenslanders in 2016.

<sup>20</sup> Queensland Health. 2018. The health of Queenslanders 2018. Report of the Chief Health Officer Queensland. Queensland Government. Brisbane.

<sup>21</sup> Australian Institute of Health and Welfare. 2018. Deaths in Australia. Canberra.

## Specialist palliative care

The demand for specialist palliative care has steadily increased in Queensland over the last five years in both private and public hospitals. The public health system has historically provided the majority of specialist palliative care (Table 5).

*Table 5. Specialist palliative care separations for all ages by facility type 2013-14 to 2017-18.*

Facility type	2013-2014	2014-2015	2015-2016	2016-2017	2017-2018
<b>All</b>	10,400	10,784	10,385	10,672	11,438
<b>Public</b>	8,051	8,388	8,488	8,438	8,897
<b>Private</b>	2,349	2,396	1,897	2,234	2,541

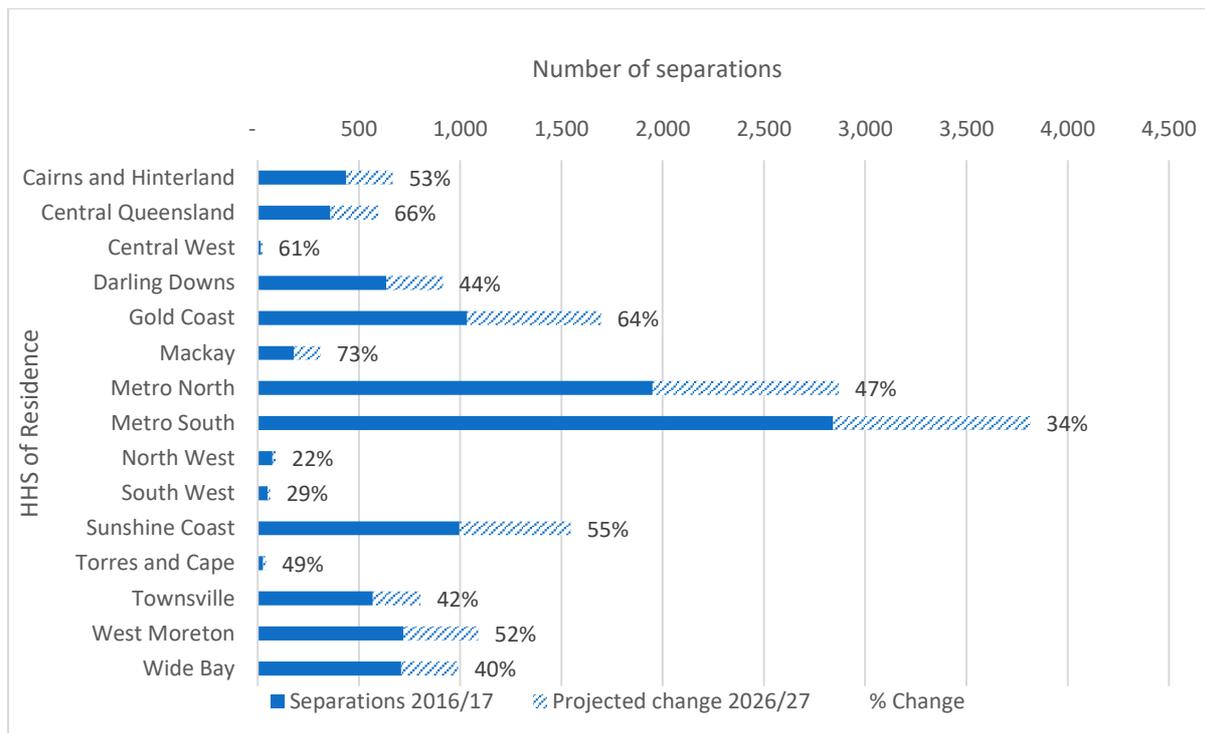
Source: Analysis of Palliative Care Demand prepared by Health Service Research, Analysis and Modelling Unit, System Planning Branch, Strategy, Policy and Planning Division, December 2018.

The total demand for specialist palliative care in Queensland is projected to grow by approximately 5,000 separations by 2026-27, with the bulk of this growth expected in public hospitals (Figure 1).

Modelling suggests that HHSs projected to experience the greatest relative growth in demand for specialist palliative care include Mackay, Central Queensland, Gold Coast and Central West. Metro South and Metro North HHSs will experience the greatest absolute growth in the number of specialist palliative care separations, and will generate the greatest volume of bed days.

It is important to note that the projections of future admitted patient activity are based on historical trends of separation rates and lengths of stay, place of residence variations in the utilisation of services and patient flow patterns. Projections are not intended to function as exact forecasts, but to give an indication of what might be expected if the stated assumptions were to apply over the projected time frame.

Figure 1 Projected requirement for specialist palliative care for all ages, all facilities, all funding types by Residence, change from 2016-17 to 2026-27



Source: Analysis of Palliative Care Demand prepared by Health Service Research, Analysis and Modelling Unit, System Planning Branch, Strategy, Policy and Planning Division, December 2018.

## Outpatient

Demand for palliative care sessions in outpatient settings, such as a clinic or via telephone continues to remain high, with almost 83,000 sessions held by specialist medical, nursing, allied health and community staff in 2017-18.

## Medicare Benefit Scheme

The MBS is an important part of the health system in Queensland. It helps to support Queensland’s palliative care system by funding professional attendances at consulting rooms or hospitals for a specialist, or consultant physician, in the practice of his or her specialty of palliative medicine.

In 2017-18, Queensland recorded 20,354 attendances by a specialist or consultant physician in the specialty of palliative medicine.<sup>22</sup> This was comparative to New South Wales which recorded the same number of attendances (Table 6).

<sup>22</sup> Australia Government, 2018, Item numbers 3005, 3010, 3014, 3018, 3023, 3028), prepared by System Planning Branch 21 February 2019.

Excludes: Case conference by a recognised specialist or consultant physician in the specialty of palliative medicine (3032, 3040, 3044, 3051, 3055, 3062, 3069, 3074, 3078, 3083, 3088, 3093) and

*Table 6 Medicare Benefit Schedule professional attendances for a specialist or consultant physician in the practice of his or her speciality of palliative medicine*

NSW	VIC	QLD	SA	WA	TAS	ACT	NT	TOTAL
20,519	11,197	20,354	3,299	17,249	3,077	914	167	<b>76,776</b>

Source: Australian Government Department of Human Services, 2018.

## Workforce demand and supply

The palliative care workforce is made up of several health professional groups including specialist palliative medicine physicians, nurses, GPs, allied health, pharmacists, other medical specialists (such as oncologists and geriatricians), and other health workers, support staff and volunteers.

While there have been moderate increases to some of Queensland's palliative care workforce over recent years, this is offset by an ageing workforce and maldistribution of staff that favours South East Queensland.

As pressure continues to grow on the health system in response to service demand, consumer expectations and an ageing population, so will the demand for workforce models and skills that can adapt to changing circumstances.

### Nursing

The National Health Workforce survey undertaken in 2017<sup>23</sup> revealed that there are 704 registered nurses and enrolled nurses across Queensland whose primary role is in palliative care, and the majority work in the public health system.

Most palliative care nurses work in a hospital setting, followed by a community health care service setting and hospice. Closer examination of job setting by location shows clustering of the workforce in South East Queensland.

The annual growth for palliative care nurses in Queensland (public and private combined) has exceeded five percent between 2013 and 2016. In keeping with past trends, modelling based on five percent annual growth to describe the volume of new skilled staff required to meet future growth, shows the need for 70 additional nurses per annum in the short term (2021) and 74 additional nurses per annum over a longer horizon to 2026.

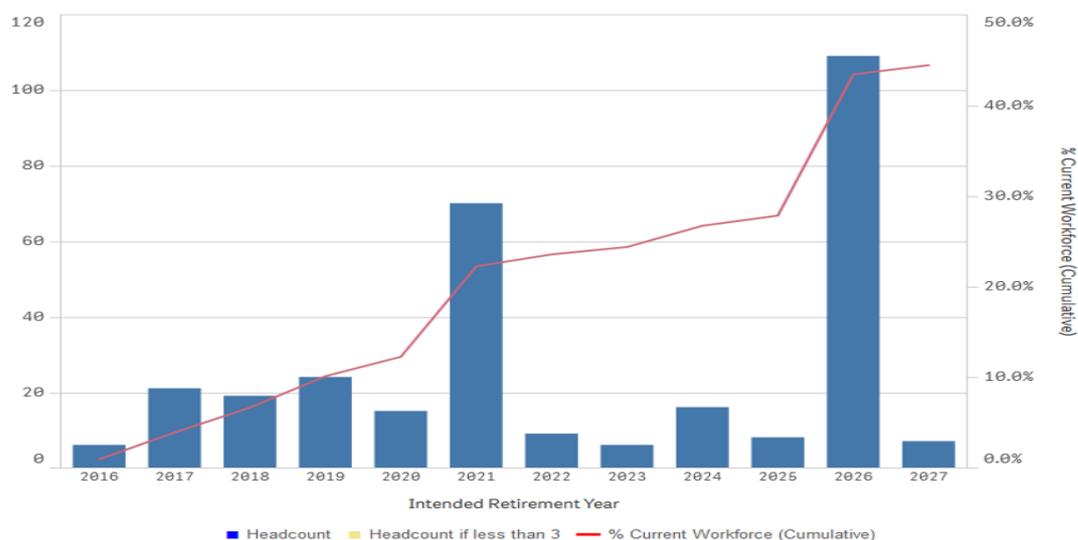
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GP Management Plan items (721 and 732) or Team Care Arrangement items (723 and 732) for that patient. Available: <http://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&q=3028&qt=ItemID>.

<sup>23</sup> Australian Health Practitioners Regulation Authority. 2017 National Health Workforce survey. Extracted by Workforce Planning Branch November 2018. Unpublished.

With just over one third of the workforce aged 55 years and over, it is not surprising that a large proportion of palliative care nurses expressed their intention to retire over the coming decade. This is representative of expected losses (Figure 2).

Figure 2 Retirement of Queensland palliative care nurses, 2016-2026.



Source: Australian Health Practitioners Regulation Authority. National Health Workforce Data set 2013-2017. Extracted by Workforce Planning Branch November 2018. Unpublished.

### Palliative medicine specialists

There are 49 palliative medicine specialists practicing in Queensland who work predominantly in a hospital setting for the public health system.<sup>23</sup> The greatest number of specialists are found at Metro North, followed by Metro South, Gold Coast and Townsville HHSs.

While Queensland experienced exceptional growth of approximately 80 percent between 2013 to 2017, modelling suggests a large undersupply of palliative medicine specialists over the coming decade (Table 7).

Table 7. Palliative medicine specialist workforce projections 2017-2027.

Medical Specialty	Year	Projected Supply	Projected Demand	Projected Gap	Relative Gap	Qualitative assessment
Palliative Medicine	2021	43	56	-13	-23%	Large Undersupply
Growth Rate 5%	2027	49	72	-23	-32%	Large Undersupply

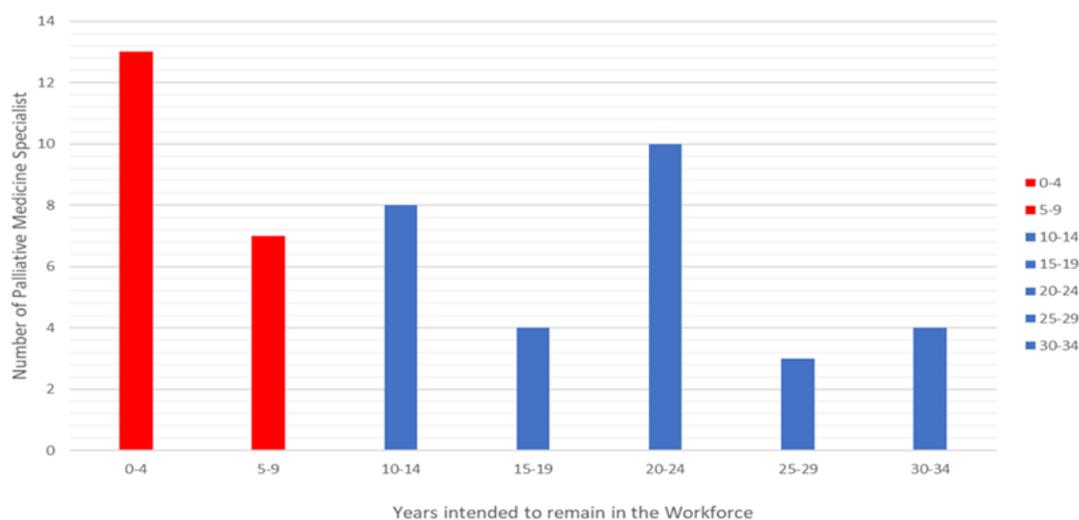
Source: Australian Health Practitioners Regulation Authority. National Health Workforce Data set 2013-2017. Extracted by Workforce Planning Branch November 2018. Unpublished.

Modelling is based on a five per cent annual growth rate and assumes medical training input consistent with the reported 2016 training numbers will continue. This has resulted in a projected shortfall of 13 (23 percent) in 2021 increasing to 23 (32 percent) in 2027.

The proportion of palliative medicine specialists aged 55 years and over has continued to decrease over the last five years, with the majority of specialists aged 45-49 years.

Twenty of Queensland's palliative medicine specialists have expressed intention to retire within the next 10 years, and of these, 13 indicated an intention to retire within the next four years (Figure 3).

*Figure 3 Retirement of Queensland palliative medicine specialists.*



Source: Australian Health Practitioners Regulation Authority. National Health Workforce Data set 2013-2017. Extracted by Workforce Planning Branch November 2018. Unpublished.

### **Allied health**

A diverse range of allied health disciplines are involved in the delivery of palliative care including dietitians, music therapists, occupational therapists, physiotherapists, psychologists, social workers and speech pathologists.

While Queensland's allied health workforce participated in the 2017 Australian Health Practitioners Regulation Authority survey, only a small number of practitioners nominated their primary role as being in palliative care ( $n < 10$ ). Due to such small numbers this information cannot be reported and used in this Review for confidentiality reasons.

## Consultation Process

### Public consultation

The views of palliative care service providers, patients and their carers, and the Queensland community are integral to the development of future palliative care service arrangements that are evidence-based, practical and relevant. During the Review, the Department undertook a consultation process to engage with members of the public to seek answers to the following three questions:

- the suitability and accessibility of existing palliative care services and service models;
- the expected changes in demand for palliative care services in the future; and
- preferred palliative care service models and arrangements for the future.

A consultation paper on the Review was available on the Get Involved website from 13 July until 9 September 2018. A total of 96 submissions were received in response to this paper. Of those submissions, the breakdown of respondents was as follows:

- consumers of palliative care services (patients, family members and carers) – 18;
- providers and deliverers of palliative care services (medical professionals (specialists, GPs, nurses), allied health professionals, HHSs, NGOs, RACFs, alternative medicine practitioners and volunteers) – 55; and
- other interested stakeholders (researchers, foundations, professional bodies, advocates, peak bodies, Primary Health Care Networks (PHNs) and faith-based groups) – 23.

## Stakeholder consultation

Departmental staff also undertook face-to-face consultations with HHSs, PHNs and NGOs who undertake palliative care services and have contracts with the Department. Consultation involved face-to-face meetings with HHSs, PHNs and NGOs as well as a workshop with the NGOs.

The purpose of the consultation processes was to understand from a provider perspective how palliative care services are delivered and funded and to explore ideas about what best practice looks like, and what opportunities there are in the future for service improvement. Discussions were focussed on the same three questions that were presented as part of the public consultation process.

The outcomes from this consultation process were integrated with those from the public consultation process to establish a comprehensive understanding of perceived key barriers to the delivery of quality palliative care services and improvements that were suggested for consideration.

## Consultation outcomes

The Department considered the information provided by the community and stakeholders as part of the consultation process, extracting common themes regarding perceived barriers to the delivery of good palliative care services and suggestions for improvement. Key issues to be addressed to achieve a more person-centred, accessible and integrated system of palliative care service arrangements into the future were identified.

Many challenges or barriers to providing good, high-quality palliative care services were identified as part of the consultation process. Common challenges identified were a lack of:

- access to and availability of palliative care;
- support for providing care in people's own homes;
- available and well-trained staff;
- respect for a person's choice about their preferred place of death;
- access to GPs for RACFs residents; and
- awareness of and information about palliative care services.

It was also identified that there was inequity in the availability and level of care across the state and for certain population groups, poor integration of services across settings, increasing carer burden and difficulties in accessing Australian Government subsidised funding packages/schemes or rebates.

As part of the consultation process, suggestions were also made about improvements that could be made to better deliver palliative care services in an accessible and equitable manner. There were a wide range of ideas put forward that varied across stakeholder groups, however, some common suggestions were:

- increased availability of specialist palliative care services, beds and equipment;
- increased availability of hospice and home/community-based care options;
- better utilisation of telehealth and other digital technologies;
- increased palliative care training and education for medical professionals;
- attraction and retention strategies for the palliative care workforce;
- increased GPs involvement in delivery of palliative care services, particularly in RACFs;
- equal access to palliative care for everyone;
- more holistic, integrated, person-centred and coordinated care;

- better access to after-hours care, respite and bereavement support;
- increased education and information about palliative care services; and
- increased advance care planning.

The barriers, challenges and suggested improvements emerging from the consultation process are outlined in more detail in Attachment 1.

## Key Learnings

The information received and analysis undertaken as part of the Review was collated and resulted in the identification of five key areas of need:

- delivering high quality palliative care services that meet demand;
- supporting the palliative care sector workforce to deliver quality palliative care services;
- delivering better access to palliative care services that meets local needs;
- providing more education and information about palliative care services being delivered in Queensland; and
- working with the Australian Government to advocate for the reform of national systems and processes to better support the delivery of palliative care services in Queensland.

### Delivering high quality palliative care services that meet demand

Along with most health, ageing and social services, the demand for palliative care services is increasing with the growing and ageing population and changing disease profiles. Consistent with stakeholder feedback, the demand analysis undertaken as part of the Review revealed that the demand for specialist palliative care has steadily increased over the last five years in both private and public hospitals, and that the demand for palliative care sessions in outpatient settings, such as a clinic or via telephone, continues to remain high.

Confirmation of this increase in demand was provided in the Literature Review, which considered national and international literature to determine trends in demand for palliative care services. It noted that the Queensland population was estimated to increase between 7.9 million to 10.1 million by 2055 and that Queenslanders were expected to live longer and die older with the leading causes of death being predicted to change, resulting in more people dying of conditions with a slower trajectory, such as dementia.

These changes will impact the volume and types of palliative care service delivery required in Queensland in the future. The Literature Review also noted that, based on mortality data, it is estimated between 41-76 percent of people living with life-limiting illness could benefit from having access to palliative care services.

The high level of need for palliative care services is also highlighted in Palliative Care Australia's *Palliative Care Service Development Guidelines* (the Guidelines)<sup>6</sup>. The Guidelines note that, "almost one in three people aged 65 years and over lives with three or more chronic diseases. Multimorbidity increases the complexity of patient needs, which has implications for all health professionals..." The Guidelines also notes that, based on 2016 data, it is estimated that approximately 160,000 people die each year in Australia and that about 75 percent of all deaths (120,000 people) are expected and therefore might benefit from palliative care services.

The data from these sources consistently demonstrate the high and increasing level of need for palliative care services. A common theme from the Review was the need to accommodate this increase in demand through the provision of services in a range of different settings, facilitating increased accessibility and availability of palliative care in a manner that also allows individual choice regarding the type of care that is provided.

The need for increased services in a range of settings is also highlighted by Palliative Care Australia in the Guidelines, which state that it is expected that government will introduce strategies to improve access to community-based palliative care services. It also notes that several strategies may need to be implemented to improve access to care such as policies and funding that increase: the provision of community-based palliative care services, outreach specialist palliative care support services, and educational and other strategies to support GPs and other providers to provide palliative care services on an in-reach basis within the community.

Increasing the availability of palliative care services is also a key deliverable highlighted in the *National Palliative Care Strategy*, which includes a goal focussed on ensuring appropriate and effective palliative care services are available to all Australians on a needs basis.

The evidence, research and analysis contained in these key strategic documents support the finding from the Review that the demand for multidisciplinary, person-centred, needs-based and high-quality palliative care services is increasing.

## Supporting the palliative care sector workforce to deliver quality palliative care services

The availability of an accessible, specialist and sustainable palliative care workforce is a critical component of delivering quality palliative care services. The consultation process highlighted the importance of ensuring there are sufficient palliative care providers and workers and that these workers need to be supported and trained so that there is the required level of capacity and capability for delivering palliative care services in Queensland.

The analysis undertaken during the Review revealed that the palliative care workforce is ageing and is concentrated largely in South East Queensland. A large proportion of palliative care nurses also expressed an intention to retire in the coming decade. As demand for services increases, further demands will be placed on the workforce. A key need identified as part of the Review focusses on the importance of supporting the sector to implement staff attraction and retention strategies to address workforce shortages, as well as education and training to address capability issues, ensuring the delivery of quality services.

In line with this need, the Queensland Health strategic vision document, *My health, Queensland's future: Advancing health 2026*<sup>24</sup>, acknowledges the existence of workforce shortages, which highlights the challenge to explore new ways to deliver services. A key deliverable noted in the document was the delivery of a 10-year Health Workforce Strategy. The Queensland Health *Snapshot Advancing health service delivery through workforce: A strategy for Queensland 2017-2026*<sup>25</sup> and *Advancing rural and remote service delivery through workforce: A strategy for Queensland 2017-2020*<sup>26</sup> documents were subsequently produced. Within these workforce strategies it notes that the “delivery of quality, consumer-centred healthcare requires a capable, organised and engaged workforce.” The vision of the strategy is, “A health workforce that is skilled and responsive to patient needs and demand; sensitive to the role of emerging technologies and changing models of care; and delivered efficiently with the best use of resources.” This vision supports the need identified during the Review for the palliative care sector workforce to be supported to deliver quality palliative care services.

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<sup>24</sup> Queensland Health, 2016. *My health, Queensland's future: Advancing health 2026*. Brisbane.

<sup>25</sup> Queensland Health, 2017. *Snapshot – Advancing health service delivery through workforce: A strategy for Queensland 2017-2026*. Brisbane.

<sup>26</sup> Queensland Health, 2017. *Advancing rural and remote service delivery through workforce: A strategy for Queensland 2017-2020*. Brisbane.

The Literature Review also identified the need to increase workforce capacity to deliver quality palliative care as a key priority for the future.

The importance of investing in a skilled and capable palliative care workforce is also highlighted within the *National Palliative Care Strategy*. The Strategy notes that, to deliver high quality palliative care, an adequate number of appropriately skilled providers must be available. In alignment with the findings from the Review, the Strategy also states that issues such as increasing demand, an ageing population and workforce shortages will all impact on the delivery of quality services in the future.

The availability of an adequate number of capable palliative care staff is the basis of Standard nine of Palliative Care Australia's *National Palliative Care Standards*. This stipulates that staff should be qualified and supported in their roles and to undertake further training and development. Furthermore, the supporting Guidelines note that Palliative Care Australia have set a benchmark of two full time equivalent specialist palliative medicine physicians per 100,000 population. With an estimated resident population of over five million<sup>27</sup>, and 49 palliative medicine specialists practicing in Queensland<sup>28</sup>, Queensland currently has a deficit of approximately 50 specialist palliative medicine physicians when compared to this benchmark. Meeting this benchmark is a challenge given the demand issues that are impacting the palliative care sector.

As is also highlighted in the Guidelines, education and training are essential components for providing a quality palliative care workforce. Specific skills and knowledge are required to become a palliative care worker and ongoing training and learning needs to be undertaken to maintain and enhance this knowledge and these skills. Supporting these workers to undertake a job, which at times can be demanding and stressful, is also important.

The evidence, research and analysis contained in these strategic documents supports the finding from the Review that supporting and growing the palliative care workforce is a critical component of ensuring there is a high-quality palliative care system in Queensland.

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<sup>27</sup> Queensland Government Statistician's Office, Queensland population counter, Available at <http://www.qgso.qld.gov.au/products/reports/pop-growth-qld/qld-pop-counter.php>, Accessed 18 February 2019.

<sup>28</sup> Australian Health Practitioners Regulation Authority. 2017 National Health Workforce survey. Extracted by Workforce Planning Branch November 2018. Unpublished.

## Delivering better access to palliative care services that meets local needs

All Queenslanders who require palliative care services should be able to access services regardless of where they live, their cultural background, type of medical condition and their socioeconomic status. However, during the consultation process undertaken as part of the Review, stakeholders identified many challenges in providing equal access to palliative care services across Queensland, including geographical remoteness, workforce attraction and retention, and varying availability of support services, such as GP and allied health. Inequality in the provision of palliative care services is also highlighted in Palliative Care Australia's Guidelines, which note that there are significant geographic disparities in access to specialist palliative medicine physicians between and within states and territories, and across metropolitan, rural and remote areas.

The Literature Review also reiterated the challenges that exist for better addressing the needs of rural and remote palliative care patients, including travel distance and workforce availability. It noted that effective delivery of healthcare in rural and remote communities requires supportive policy, established Australian Government and State relations, and community readiness to be in place. It also acknowledged the benefits telehealth can provide to these communities through improved access to healthcare services and expertise.

The challenges to the delivery of health services and building and maintaining sustainability within the workforce in rural and remote areas are also highlighted in the Department's strategy, *Advancing rural and remote service delivery through workforce: A strategy for Queensland 2017-2020*<sup>26</sup>. Small populations with diverse health needs, dispersion of communities and services and a small health workforce adds complexities that must be considered when managing the workforce. The Strategy outlines an integrated planning approach to implementing initiatives that are aligned with other key strategic documents to achieve its objective of, "positioning the rural and remote health workforce to deliver contemporary, appropriate and safe health services for rural and remote communities".

The importance of considering the potentially diverse needs of people needing palliative care services is articulated in the *National Palliative Care Standards*.<sup>7</sup> The Standards acknowledge the importance of recognising the needs of people who may be vulnerable or at risk, including, but not limited to, Aboriginal and Torres Strait Islander peoples, people with disability, people experiencing homelessness, and people seeking asylum.

In addition, many people living with non-malignant, life-limiting conditions are not currently getting access to specialist palliative care services, but experience similar symptoms to those

living with cancer. These people would also benefit from specialist palliative care interventions. Palliative Care Australia's Guidelines state that there needs to be significantly increased access to specialist palliative care services for people dying from causes other than cancer.

These considerations highlight the need for person-centred, needs-based care, which is stated in the National Palliative Care Standard number four: "The provision of care is based on the assessed needs of the person, informed by evidence and is consistent with the values, goals and preferences of the person as documented in their care plan."

Outcomes from the Review and Palliative Care Australia's Standards and Guidelines highlight the importance of needs-based care that is focused on the person and delivered in a culturally-responsive way, regardless of a person's diagnosis, ethnicity, location or other factors not related to the assessment.

## Providing more education and information about palliative care services being delivered in Queensland

Through the Review consultation process, stakeholders highlighted the importance of frequent, comprehensive and easily-available information about palliative care services for individuals, families and carers. Also highlighted was the importance of efficient and effective case management strategies being implemented to support quality care for individuals. Stakeholders also noted the value of sharing information about learnings and innovations in the delivery of palliative care services across the palliative care workforce to help ensure that good ideas are built upon and expanded.

The Literature Review supports these comments from stakeholders and noted that one element of best practice was appropriate case management and coordination of care. It was also noted in the Literature Review that an integrated and consultative approach to delivering palliative care services was found to be associated with better end-of-life care and that increasing palliative care awareness and understanding was a priority for improving palliative care.

The importance of increasing awareness and understanding about palliative care, including among health professionals and carers is highlighted in the *National Palliative Care Strategy*. Within the document, it also notes that it is important that this communication is undertaken in a culturally respectful manner.

Appropriate and timely communication and support, as well as integrated care, are noted as important components of a high-quality palliative care system within Palliative Care Australia's *National Palliative Care Standards*. The standards noted that:

- a partnership approach (including the person, their family and carers) should be undertaken when developing care plans and making decisions about this plan;
- families and carers need to have access to bereavement support services and appropriate information; and
- care needs to be integrated to ensure seamless transitions within and between services.

People requiring palliative care often must transition between different settings and it is important that systems are implemented to make the coordination of care during these transitions as seamless as possible. Given that people have a wide range of palliative care needs, frequent communication is needed between palliative care providers and individuals, families and carers to support them during their care journeys.

The evidence, research and analysis support the finding from the Review that there is an ongoing need to provide comprehensive and timely information about palliative care services for individuals, families and carers throughout their palliative care journeys. There is also a demonstrated need to increase awareness of, and education about, palliative care services among the general community and health professionals that are not directly involved in the delivery of these services.

## Working with the Australian Government to advocate for the reform of national systems and processes to better support the delivery of palliative care services in Queensland

The Australian and Queensland Governments both have important roles to play in the funding and delivery of palliative care services in Queensland. Some of the suggested actions raised by consumers, providers and other stakeholders as part of the Review are the Australian Government's responsibility and would need to be referred to the Australian Government for consideration.

Examples of suggested actions were the reform of the MBS and the ACFI to better allow high quality palliative care by GPs and in RACFs, which are Australian Government responsibilities. Stakeholders also suggested the potential for introducing palliative care specific home care packages.

The Department will continue to advocate with the Australian Government about these actions at appropriate national forums, such as the COAG Health Council and the Australian Health Ministers' Advisory Council.

The Department will also continue to work with the Australian Government to respond to key policies such as the updated *National Palliative Care Strategy (2018)*<sup>3</sup> and recommendations from the *Productivity Commission Inquiry Report into Human Services: Reforms to Human Services*<sup>8</sup>.

## Next Steps

Ensuring that all Queenslanders and their families have access to the care and support they require at the end of life is a priority for the Department.

The Department already provides funding to NGOs to assist them to deliver palliative care clinical services within the community. As an outcome from the Queensland Health Palliative Care Services Review, the Department will provide additional funding from 2019-20 to 2022-23 to the seven non-government organisations that deliver palliative care clinical services and receive funding from the Department. Specifically, these organisations are:

- Cittamani Hospice Service
- Ipswich Hospice Care Inc
- Hopewell Hospice Services (now part of Wesley Mission Queensland)
- Karuna Hospice Service Ltd
- Little Haven Cooloola Sunshine Coast Palliative Care Association Inc
- St Vincent's Private Hospital
- Toowoomba Hospice Association Inc.

The provision of additional funding will assist in delivering outcomes related to:

- increasing supply of clinical palliative care services;
- improving consumer choice in relation to community-based palliative care services; and
- building the sustainability of the NGO service delivery sector.

It is important to note that palliative care services involve a range of options depending on the patient's needs. The provision of services in the community is only one component of an overall system for palliative care service delivery.

Providing information about the findings from the Review to the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee (the Parliamentary Committee) will ensure that the Parliamentary Committee is able to consider the valuable input gathered and analysed as part of the Review process.

It is envisaged that the findings from the Review will assist the Parliamentary Committee in the development of recommendations to further strengthen Queensland's health system to produce positive outcomes for patients, their families and carers, as well as palliative care staff and volunteers.

# Attachment 1 - Consultation Outcomes

## Challenges to the delivery of good palliative care services

### Consumers' perspectives

Consumers stated that barriers were:

- lack of respect for and implementation of patients' choices regarding place of death;
- a lack in quality and availability of care - inadequate training, experience, or availability of palliative care staff when required;
- inequities in access to palliative care services, particularly in rural/regional/remote/areas;
- low community awareness and lack of information about palliative care and palliative care services;
- carer burden;
- lack of access to equipment for care at home;
- lack of hospice, respite facilities, afterhours care, and residential care;
- difficulty in accessing schemes/funding/rebates for palliative care;
- poor communication, continuity, and integration of care by the health system; and
- lack of availability of palliative care beds in hospital.

### Providers' perspectives

Providers noted that:

- demand is outstripping supply, requiring greater investment in service delivery by Australian and State Governments;
- equity of access is influenced by geographical location and the level of sophistication in the integration of services across primary, aged care and specialist palliative care;
- attracting and retaining a skills workforce is more difficult in regional and remote areas;
- demand is currently managed by decreasing the length of time palliative care services are provided to each patient and limits the quality of care provided;

- there is a lack of 24-hour community nursing services to support people in their own homes;
- The wait list for Australian Government-subsidised Home Care Packages is too long to support palliative care provision in the home; and
- lack of access to GPs for RACF residents limits the proportion of residents with an advance care plan or who receive good palliative care.

### Other interested stakeholders' perspectives

Other interested stakeholders advised that there is:

- insufficient inclusion of allied health professionals in palliative care teams;
- poor integration of services across settings;
- lack of consistent data collection about palliative care services;
- lack of inclusion of non-malignant disease types in palliative care services;
- workforce shortages across all areas and settings;
- rural, regional and remote underservicing;
- lack of community information and preparedness for end-of-life;
- lack of access to palliative care for marginalised populations;
- increasingly complex patient care needs;
- carer burden; and
- insufficient resources to allow patient choice to die at home.

### Suggested improvements for the delivery of better palliative care services

#### Consumers' perspectives

Key areas identified for improvement by consumers included:

- greater availability of specialist palliative care services and beds;
- greater availability of home/community-based care options and equipment;
- greater emphasis on advance care planning;
- greater consideration of the needs of families and carers;

- better coordinated and integrated care;
- greater ability to access services locally;
- more holistic approach to the delivery of palliative care;
- increased palliative care training and education for doctors (including GPs) and nurses to improve quality of and availability of care;
- provision of clear information and real choices for patients and families to enable a patient-centred approach;
- increased community education about palliative care;
- more access to hospice facilities and other home-like residential environments at end-of-life;
- equal access to palliative care services regardless of the HHS region or community that is lived in;
- better access to afterhours care;
- better access to respite and support for carers; and
- more rural palliative care services.

## Providers' perspectives

Key suggestions made by providers included:

- increase funding for community-based palliative care;
- build capability and capacity in the clinical workforce;
- identify attraction and retention strategies for palliative care workforce;
- develop regional and remote models of care to support patient choice and outcomes;
- increase GP involvement to support palliative care service delivery in the home and RACFs;
- increase availability of dedicated hospital and hospice palliative care beds;
- increase community awareness and education on palliative care choices and patient journey;
- increase bereavement support in the hospital and community;
- increase utilisation of telehealth and other digital technologies, particularly in rural, regional, and remote areas;

- enablement of more holistic care models for palliative patients, including access to allied health and spiritual care;
- improve data collection and analysis processes, research, and consistency in reporting on palliative care outcomes;
- increased promotion of advance care planning;
- increased investment and access to carer respite;
- Australian Government review of MBS and ACFI items to better allow high quality palliative care by GPs and in RACFs;
- increased consideration of vulnerable population groups in palliative care planning; and
- improved communication, collaboration and integration between health professionals and locations regarding palliative patient care.

### Other interested stakeholders' perspectives

Key ideas raised by other interested stakeholders were:

- tailor palliative care services to vulnerable populations;
- increase attention on advance care planning;
- population-based models of care;
- patient-centred service design;
- ensuring RACFs are supported by palliative care services;
- increasing home-based care options;
- consistency in palliative care data collection;
- greater allied health professional inclusion in palliative care teams;
- recruitment and retention of more palliative care doctors and nurses;
- greater funding of both specialist and community-based palliative care;
- more education and training of medical staff about palliative care;
- better integration of care across settings;
- improvements in the use of telehealth; and
- greater use of holistic models of care.