

Palliative Care in Queensland 2019 Regional and Rural



RAPID CONSULTATION FINDINGS REPORT



PalliativeCare
QUEENSLAND

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Palliative Care Queensland (PCQ) acknowledges the Traditional Custodians of the lands and seas on which we live and work, and pay our respects to Elders past, present and emerging.

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Queensland
Government

Palliative Care Queensland wish to acknowledge the generous support from the Queensland Government in funding this project.



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“We believe that the way we care for our dying is a significant indicator of the kind of society we are.”



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QUEENSLAND

About Palliative Care Queensland

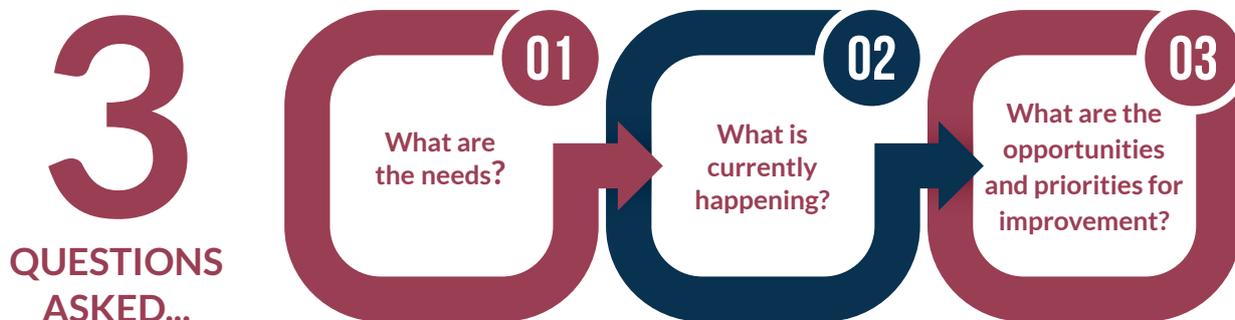
Palliative Care Queensland (PCQ) is the peak body for palliative care in Queensland. PCQ has been operating for over 30 years, has over 400 members and is a founding member of Palliative Care Australia. PCQ members include health professionals across all sectors of health, specialist and generalist palliative care services, aged care, disability care, peak bodies, as well as consumers and interested members of the Queensland community. Collectively, the PCQ membership body holds tremendous knowledge and wisdom about the challenges the sector faces and the opportunities those challenges can bring.

Our priorities are that:

- All Queenslanders are able to live every day until their last
- All Queenslanders are able to have a dignified death, regardless of their illness, age, culture or location
- All Queenslanders have access to a supportive social network at the end phase of life and have the choice of quality palliative care

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PALLIATIVE CARE IN QUEENSLAND 2019 - REGIONAL AND RURAL STAKEHOLDER SAMPLE AND DATA SOURCES



DURING 1 MONTH CONSULTATION TIME FRAME

137
people gave direct input into this rapid consultation

312
services and supports were mapped

72
journal articles were reviewed

6 METHODS OF CONSULTATION UTILISED



Executive Summary

Palliative Care Queensland (PCQ) was funded by Queensland Health to conduct a rapid consultation in June 2019 to gain an understanding of the following core questions in relation to palliative care in regional and rural Queensland:

- What are the needs?
- What is currently happening?
- What are the opportunities and priorities for improvement?

Over a one-month period, PCQ conducted a rapid consultation using the following methods:

- Literature review
- Desktop service mapping
- Community-led community consultation: Kitchen Table Discussions
- General consultation: Online survey
- Sector consultation: Staff room conversations
- Sector consultation: Key stakeholder qualitative interviews

Stakeholder sample and data sources

- 137 people gave direct input into this rapid consultation
- 312 services and supports were mapped
- 72 journal articles were reviewed



“The system is so difficult to navigate, every time you think you can find some help there is another number to call, you can't do it because you need their permission, another website, it is so impersonal and difficult and draining, and things are hard enough.”

Consumer

Project background

During 2018, the Department of Health (the Department) undertook the Queensland Health Palliative Care Services Review (the Review) which sought to identify current and future palliative care service's needs to inform the development of a strategic approach to future palliative care services arrangements.

In September 2018, the Premier and Minister for Trade announced a Parliamentary Inquiry into aged care, palliative care and end-of-life care (Parliamentary Inquiry). The Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee (Parliamentary Committee) was asked to examine these issues.

Findings from the Review will be used to inform the Parliamentary Inquiry so that the Parliamentary Committee will be able to consider the valuable input from all the stakeholders who contributed to the Review process when making their deliberations.

One of the key findings from the Review was the need to help deliver better access to palliative care services for Queenslanders regardless of where they live. A common theme in the feedback received as part of the consultation process was that there was limited availability of palliative care services in regional and rural areas, and that the services that were provided were not at the same level as those within South East Queensland. This suggested that access to palliative care services was inequitable across the State.

Given the key findings from the Review and the likely focus for the Parliamentary Committee in relation to the delivery of palliative care services in areas of the State outside of South East Queensland, it is considered timely that further policy work be undertaken to inform any future investment in palliative care services in regional, and rural areas of the State.

Project scope

The Department already holds some data relating to demand for palliative care services, and information about best practice palliative care service delivery models, which was generated as part of the Review.

To build on this knowledge it has been determined that further information is required about best practice palliative care service delivery in a rural and regional context and about the capacity and capability of the palliative care sector to deliver these services.

Project limitations

This rapid consultation is not without its limitations and should be read in the context of a short timeline (4 weeks), limited resources and capacity of the sector to engage. For example, this rapid consultation was not able to engage the private sector. This consultation has provided some baseline information, PCQ recommends a similar consultation with an increased timeframe to occur every two years to determine improvements for regional and rural services.

Project definitions

- Regional and rural services
 - o Defined [using ASGS remoteness areas \(2016\)](#)
 1. Regional Services: RA2 RA3 – Inner and outer regional Australia
 2. Remote Services: RA4 RA5 – Remote and very remote Australia
- Palliative care services and supports – includes:
 - o Specialist palliative care services
 1. Level 2 and 3 specialist palliative care services
 - Defined by the [Palliative Care Service Delivery Guidelines 2018](#) page (26 and 27)
 - o Generalist palliative care services
 1. Level 1 palliative care services
 - Defined by the [Palliative Care Service Delivery Guidelines 2018](#) (page 25)
 - o Palliative care supports (informal or formal)
 1. Includes community initiatives which provide support for people experiencing loss, ageing, dying and grief

Project framework

The project was designed to address the following three questions:

1. Where is the need?

- What are the key areas of need and vulnerable groups in relation to palliative care provision in regional and rural Queensland?

2. What is currently happening?

- Who is currently delivering palliative care services in regional and rural Queensland?
- What are the current key innovations and improvement initiatives in palliative care in regional and rural Queensland?
- What is best practice in palliative care service delivery in regional and rural areas?

3. What are the opportunities and priorities?

- What are opportunities for future improvement and innovation for palliative care in regional and rural Queensland?
- What would be needed for the sector to scale up these activities?
- What is the ability/capacity of the sector to scale up activity and provide more services in regional and rural areas?
- What are the recommended priorities to improve palliative care in regional and rural Queensland?

LITERATURE REVIEW

Purpose of the literature review

The purpose of the literature review was to identify the key areas of need and vulnerable groups in relation to palliative care provision in regional and rural Queensland. Specifically, the literature review aimed to identify the key innovations and improvement initiatives in palliative care in regional and rural Queensland, as well as identify what is best practice in palliative care service delivery in regional and rural areas.

Due to the consultation timeframe, only published articles from peer-reviewed literature were reviewed. Search terms to identify relevant articles include: 'palliative care', 'hospice', 'terminal care', 'end-of-life', 'end-of-life care', 'regional', 'remote', 'service', 'service deliver', 'model of care' and 'program'. A total of 72 articles were included in this review.

Key findings

The main findings from the literature review are summarised as follows:

- Rural patients suffer significant financial burden and isolation from their community when required to access specialist palliative and end of life care in urban areas
- Rural patients often adopt a 'we make do' attitude which results in reluctance to proactively seek timely pain and symptom management – greater likelihood of hospital admissions for end of life care and dying in hospital
- Family caregivers who do not have access to interdisciplinary team support suffer significant carer burden
- First Nations people's stressors are magnified
- Models of care that demonstrate acceptability and feasibility in urban areas are unlikely to integrate well into isolated communities

Conditions for success and models of care for regional and rural areas – international exemplars were identified as the two components to successful introduction and delivery of palliative and end of life care in regional and rural communities.

The five conditions for success that emerged from the literature review were: the role of place, responding to culture, developing community readiness, building on what already exists and integrating education. These conditions for success were identified as crucial components to consider during preparatory work and prior to any integration of service planning.

Five models of care were identified that contributed to the delivery of and enhanced access to palliative care in regional and rural areas. These five models of care are: shared care models, nurse led services, telehealth, palliative care volunteers and models for First Nations communities.

DESKTOP SERVICE MAPPING

Purpose of the desktop service mapping

The purpose of the desktop service mapping was to identify what services and supports could be found online in regional and rural areas of Queensland and to identify who was providing the services as well as what type of services are being provided.

A desktop review was conducted through six online community directories:

- <https://palassist.org.au/>
- <https://palliativecareqld.org.au/find-a-service/>
- <https://www.healthdirect.gov.au/>
- <https://www.mycommunitydirectory.com.au/>
- <https://palliativecare.org.au/directory-of/services>
- <https://www.health.qld.gov.au/system-governance/health-system/hhs>

In addition, Queensland Health remote Hospital and Health Services were reviewed, and statewide and national palliative care projects shared their mapping activity results.

A total of 312 support services including helplines and websites were found, and included in the desktop review for regional and rural Queensland.

Key findings

- Lack of consistency in mapping
- Inaccurate information on the web
- Current directories and information are likely to create increased access issues to palliative care
- Current mapping likely to result in confusion for both health professionals and consumers
- Nil Australian standardised palliative care service mapping tools available



Community consultation:

KITCHEN TABLE DISCUSSIONS

Purpose of the kitchen table discussions

The purpose of Kitchen table discussions was to provide community members who may not normally have a say, an opportunity to have their voice heard in an informal, friendly and safe setting. Kitchen Table Discussions are an engagement tool that provide the information and guidance needed to support individuals and small group participation in discussions at a place and time of day that suits them; and which is led by a community member (the Kitchen Table Discussion Host). The Kitchen table conversations consisted of five consumers and carers chosen to host sessions within tight timeframes in five Queensland locations. The locations chosen were Hervey Bay, Mount Isa, Chinchilla, Wandoan and Barcaldine. A total of 41 consumers were consulted. The outcomes of each discussion were collated by the hosts and provided to Health Consumers Queensland for inclusion in this report.

Key findings

Knowledge, information and education

Respondents indicated that there is a need for more information and education on what palliative care is – including the stages of palliative care, how to access it and what services and extra supports are available. There is varied understanding on what type of services are expected to be included in a palliative care service.

Access

Some respondents indicated that they have some knowledge of services within the region whilst others had no knowledge of available services.

Workforce

Respondents identified the need for more specialist palliative care doctors and nurses, along with training of outreach health workers and those who can assist people to get to the next step with Palliative Care - especially those educated in palliative care and able to provide home-based care. Respondents indicated that there is a lack of availability of trained palliative care nurses to be able to provide home-based care to those living on rural properties, particularly farmers, due to distance.

Equipment – access to

Respondents indicated there is a need for people receiving care at home to have better access to equipment in terms of availability, knowledge on how to use it and where to get equipment from. There is a need for better access to equipment locally with transport and maintenance available to families caring for patients within their home.

Vulnerable groups not accessing palliative care

Respondents identified several vulnerable groups:

- People living outside of townships and those who are remotely located such as on farms or remote properties
- Indigenous people
- People with a culturally and linguistically diverse background
- Older people
- Those who are financially challenged
- People too proud to ask or accept support
- People without family or support
- Younger people not accepting their diagnosis
- Riverbed people, homeless mob

- People with mental health issues and illness
- Everyone living in regional and rural areas

Key priorities to improve palliative care

Respondents indicated two main priorities to improve palliative care:

1. The need for community-based palliative care
2. Everyone being involved and better education and information being available



“

“Having genuine 24/7 telephone or video support available through specialist medical and advanced practice nursing is critical.”

Palliative Care Doctor

General consultation:

ONLINE SURVEY

Purpose of the online survey

The purpose of the online survey was to assist PCQ and Queensland Health to understand a wide range of opinions in relation to the core questions of this consultation. The Survey was open from 4th June to 14th June 2019 and comprised a range of activities designed to maximise opportunities for regional and rural community members to participate. Activities particularly focused on social media promotion and a prize incentive to complete the survey.

A total of 76 community members completed the survey.

Summary of findings

- 65% of respondents indicated they find out about palliative care information from personal experience
- 46% of respondents indicated that there are either very “limited” palliative care services available to them if they wanted to stay at home or “none available” that they are aware of
- 33% of respondents were “unsure” or “do not know” of any palliative care spiritual or social supports that are available to them
- 23% of respondents were currently aware of after-hours support for palliative care services

In addition, other comments made in the Survey indicate a lack of availability of palliative care services that is not meeting the growing demand of palliative patients/clients, and that there is limited support available outside of business hours for palliative care patients and their families.

Five key priorities were identified for palliative care in regional and rural Queensland:

1. More staff to provide 24/7 support from a nurse or other health professional during the end-of-life stage
2. More training and education is needed for palliative care staff and other health workers to provide better support for those in end-of-life stage
3. Improve access to services and supports for patients, carers and families
4. More funding/more affordable options for palliative care
5. Increase community awareness – remove the stigma of ‘death’ to normalise conversations about death

“

“Palliative care needs to be more visible”

Consumer

“

“Acknowledge pre-existing social capital”

Literature review

Sector consultation:

STAFF ROOM CONVERSATIONS

Purpose of the staff room conversations

The purpose of the Staff Room Conversations was to assist PCQ and Queensland Health to understand the sector's opinion in relation to the core questions of this consultation.

Information was collected from 9 different organisations including palliative care services (including metro, regional and rural, as well as adult and pediatric), statewide and national palliative care projects, a peak body, a national organisation, and a Primary Health Network (PHN).

Summary of findings

- Key area of need
 - Not enough palliative care workforce
 - Limited access to GPs
 - Staff already working at capacity – palliative care takes time, staff need ability to access agency/casual staff to provide the care needed
- Vulnerable groups in regional and rural Queensland
 - People living in isolated areas
 - People who financially struggle to get treatment due to the high travel costs associated with living in rural areas
 - Aboriginal and Torres Strait Islander people
- Innovation and improvement opportunities
 - Telehealth / IT opportunities
 - Flexible packages of care to improve access issues
- Conditions for success
 - Supported access
 - Support existing services to have increased staff to provide the care they need or utilise agency/casual staff if needed
 - Increase palliative care investment by Government
 - Community awareness – enable community to see palliative care as a benefit
- Supporting services to scale up
 - Providing more education and training – health professionals and community
 - Increase resources – flexible care/resource packages
 - Consistent support – enable access to specialist services for support
- Highest priority areas identified
 - More resources – with flexible packages
 - Increase health professional and community education
 - Improve access to specialist palliative care team

Sector consultation:

**KEY
STAKEHOLDER
INTERVIEWS**

Purpose of the key stakeholder interviews

The purpose of the key stakeholder interviews was to gain a qualitative understanding of the sector's perspectives in relation to the core questions pertaining to this consultation.

Approximately 500 minutes of qualitative data were collected from 11 different key stakeholders identified by Palliative Care Queensland staff and members of the State Council. Key stakeholders included specialist palliative medicine consultants, palliative care nurse practitioners, palliative care clinical nurse consultants/clinical nurse specialists, health service managers, and health portfolio holders from regional councils.

Key findings

Three themes emerged from the analysis of data provided by key stakeholders: (1) Vulnerability and unmet need in regional and rural Queensland; (2) Limitations in palliative care funding, models of care and workforce capacity; and (3) Strategies to strengthen palliative care provision in regional and rural Queensland. Together, these themes and the opportunities discussed below are reflective of the comments provided by key stakeholders.

The provision of palliative care outside of metropolitan areas is considered to be fragmented, under-resourced and inconsistent in terms of needs-based funding, continuity of care across settings, and models of care employed.

While current national initiatives such as PEPA and other local Primary Health Network collaborative projects such as Connecting End of Life Care are making a positive contribution to palliative care in regional and rural Queensland, a lack of education, communication, and sharing of knowledge/resources remains evident, due to isolation. The development of a dedicated regional and rural palliative care network could provide an opportunity to connect and offer further support infrastructure.

There are opportunities for current initiatives in some areas to be replicated elsewhere or expanded on a larger scale across the State. For example, nurse-led models of care that employ a palliative care nurse practitioner have been found to be effective and successful overall. However, they still rely on access to support from a medical consultant and allied health, and these models have only been developed in certain areas.

To improve the provision of culturally appropriate palliative care for Aboriginal and Torres Strait Islanders, there would be merit in replicating the collaborative model of care developed by the Northern Peninsular Area Family and Community Services (NPAFACS) and implementing this as the Community Based Palliative Care Program. This model features case management provided by an Aboriginal and Torres Strait Islander Palliative Care Health Practitioner, along with medical assessment and treatment provided by a NPAFACS GP, with access to a specialist palliative care consultation service provided by a palliative care physician and bereavement support from a grief and loss counsellor. However, the success of this model is contingent on community involvement.

Other opportunities include adaption of the nurse navigator model to include a dedicated palliative care role in regional and rural areas. Whilst other more system-based or disease-focused nurse navigators are in operation, it is noted that this role has not yet been implemented with a dedicated focus on navigation of the health system in a regional or rural palliative care context. Based on international evidence that supports this role, there are apparent benefits to the implementation of this. The key strategies identified to strengthen palliative care in regional and rural Queensland are:

- Make regional and rural palliative care a priority area for healthcare funding
- Build professional capacity to address unmet needs and improve palliative care outcomes
- Address inequities in access to palliative care for Indigenous Australians
- Build community capacity through community engagement and partnerships with services
- Utilise digital health technologies to develop and expand on the benefits of telehealth
- Develop infrastructure to achieve ongoing connection and communication through a supportive regional and rural palliative care network to develop a more consistent approach to developing effective models of care and to promote communication and the sharing of knowledge/resources amongst currently isolated clinicians and services



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