

*Submission to Queensland  
Health Review of Palliative Care  
Services, 2018*

*Palliative Care Queensland  
September 2018*



**PalliativeCare**  
QUEENSLAND

*“The planning of palliative care services by states and territories will ensure that there is a continuum of palliative care services that aligns people’s needs with the required workforce capability.”*

Palliative Care Service Development Guidelines, 2018

This submission to the Queensland Health Palliative Care Services Review is made on behalf of Palliative Care Queensland (PCQ). PCQ is the peak advocacy organisation for palliative care in Queensland, representing the interests and aspirations of all who share the ideal of quality care at the end of life for all Queenslanders. PCQ has been operating for 30 years and is a founding member organisation of Palliative Care Australia (PCA). As such, PCQ aspires to meet Palliative Care Australia’s national aims at State level in addition to responding to the needs of our members and the Queensland Palliative Care sector and community.

In 2017, PCQ created Queensland Compassionate Communities as its community arm, which focuses on building partnerships with local community groups to develop communities that respect and value living, ageing, dying and grieving well. Queensland Compassionate Communities has an independent advisory group that provides expert advice to PCQ’s State Council.

PCQ has a far and deep reaching profile across the state, with over 250 members, including 20 organisational members. Importantly, in the last year PCQ has engaged with over 3,000 consumers and general Queensland community members through our events such as Good Life Good Death Expos in Brisbane and Townsville, seven Dying To Know Film Nights across Queensland, a consumer forum held in South Brisbane during National Palliative Care Week 2018 and two community based surveys. PCQ routinely seeks feedback from participants at all events and enjoys significant social media engagement through Facebook, Twitter, Instagram and LinkedIn.

There are approximately 29,500 deaths in Queensland each year and a recent Productivity Commission Report<sup>1</sup> suggests that up to 90% of people who die would benefit from palliative care.

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<sup>1</sup> *Productivity Commission, 2017, Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Report No. 85, Canberra.*

**Question 1:**

*How well are palliative care services meeting the demand and service setting preferences for patients and their carers and families in your local area?*

*If you are a palliative care service provider, please indicate what types of palliative care services you currently provide and in which settings – for example, hospital, hospice, community, residential aged care, home settings; the volume of services you provide and to whom.*

***“Palliative Care Australia expects that state governments will adopt a population-based approach to the planning of palliative care services.”***

*Palliative Care Service Development Guidelines, 2018*

**People in the last phase of their life are amongst the most vulnerable members of our society. Quality care and social supports during this last phase of life and a ‘good death’ for people should be the aim of every health and social system.**

PCQ has significant concerns regarding the current Queensland service and support systems for palliative care. Specifically, the current service proposition across the state does not meet the current needs of our community. The current needs are evidenced by the Palliative Care Outcomes Collaboration data which indicate a trend of increased episodes of care across Queensland<sup>2</sup>. PCQ expects the need for all levels of palliative care services to grow in line with Queensland’s growing and ageing population.

With a societal focus on ‘life saving treatments’ palliative care is often not viewed as a ‘need’, until all other avenues of treatments have been exhausted. This is reflected in the current health system in Queensland with our members reporting that many public palliative care services staff perceive their funding is only to provide supports for people with a prognosis of three months or less.

Our members report they have witnessed an increased focus on interventions to extend/save lives. Furthermore, people are now living with increasingly complex, chronic and multi-morbid diseases<sup>3</sup> resulting in increasingly complex needs – including medical, social, financial and spiritual needs. This puts an increased burden on the health system, as well as on social services and workplaces.

Palliative care is one of many *needs* during the end phase of life, therefore should not be considered in isolation. There are opportunities for collaborations

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<sup>2</sup> *Palliative Care Outcomes Collaboration Queensland Reports. Retrieved from <https://ahsri.uow.edu.au/pcoc/reports/qld-archive/index.html> on 29 August 2018.*

<sup>3</sup> *Queensland Government Population Projections to 2031: Local Government Areas, 2011 edition, Office of Economic and Statistically Research, Queensland Treasury*

between palliative care providers and support services at the end of life<sup>4</sup> – including ageing, disability, social, community and health sectors to provide streamlined systems, services and supports which would be both cost effective<sup>5</sup> and would meet the whole needs of the people.

Current health and community systems do not provide flexible care models to respond to growing demand of people approaching the end of their lives. Palliative care service delivery models in Queensland are driven by funding paradigms which predominantly support hospital-based models of care. This is inconsistent with the purpose, philosophy and aims of palliative care which requires a needs based model of care. Queensland service models are regularly reviewed, and new initiatives are piloted, but this is usually done in isolation and without a whole of community approach.

### **PCQ calls for a better understanding of demand and consumer preferences in Queensland by:**

- Implementation of a co-design model of service development, implementation and evaluation, incorporating stronger community involvement (including local councils and community groups).
- Annual interagency forums (statewide and in each HHS) to discuss needs, initiatives and priorities for people at the end phase of life, (we acknowledge that this may be embedded in some HHSs already).
- A continual, sustainable process of needs assessment and asset mapping across the state, in order to keep data current and inform development.
- Consistent and continuous data reporting which measures consumer needs, preferences and experience.
- Development and implementation of patient and community feedback mechanisms to their service providers.
- Annual statewide community palliative care survey to measure death literacy, compassionate community activities, social impact of community initiatives, social capital and community satisfaction with palliative care services.

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<sup>4</sup> *State of Queensland (Queensland Health), 2015, Statewide strategy for end-of-life care 2015, Downloaded from: <http://www.health.qld.gov.au/systemgovernance/strategic-direction/plans/health-service/> on 25 January 2018. (Page 1: Defining end-of-life-care)*

<sup>5</sup> *Productivity Commission, 2017, Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Report No. 85, Canberra.*

**Question 2:**

*What changes could be considered to palliative care service delivery in your area that would improve the experience of patients and their carers and families?*

*If you are a palliative care service provider, please describe any plans you have for your service, or suggestions you might have to enable your service to better meet current service needs and service setting preferences.*

*“Queensland has no state-wide plan, equitable funding or service delivery framework to support the provision of palliative care across Queensland. Several service delivery models have been endorsed and promoted by the palliative care sector, however no central or regionalised service delivery model or equitable population based funding framework has been adopted by the Queensland Government.”* Palliative Care Queensland Submission to the Queensland Parliament Inquiry into Palliative and Community Care in Queensland, 2012.

PCQ contends that there has been no progress towards a specific Queensland Integrated Palliative Care Service Delivery Plan for palliative care since the 2012 Parliamentary Inquiry<sup>6</sup>. The principal issues identified during the 2012 Parliamentary Inquiry in relation to service delivery remain the same:

- Lack of care coordination across care settings and time;
- Inconsistent models of care;
- Ineffective funding and inequitable resource allocation models;
- Insufficient allied health support particularly in terms of:
  - counselling and bereavement;
  - occupational therapy;
  - physiotherapy;
  - pharmacy and
  - pastoral care.
- Insufficient access to respite services;
- Workforce shortages;
- Poor access to specialist palliative care by non-malignant diagnosis groups;
- Limited or no access for those in regional, rural and remote areas;
- Poor representation of specialist palliative medicine/care for people with advanced disease
- Lack of care-planning meetings.

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<sup>6</sup> PCQ recognises the release of the 2015 Statewide Strategy for End of Life Care which includes aspects of palliative care, however notes that this is not a specific palliative care plan, inclusive of all facets of palliative care.

Furthermore, current workforce requirements for specialist palliative care do not meet those identified by the Palliative Care Service Development Guidelines<sup>7</sup> (2018) to deliver quality palliative care.

The Statewide Strategy for End of Life Care 2015 has created some improvements for the public sector services, however while this strategy includes aspects of palliative care (such as advance care planning initiatives), it is not a statewide integrated service delivery palliative care plan, and excludes non-public services (where much of the need is located).

**PCQ calls for better palliative care service delivery by:**

- The development of a Queensland Integrated Palliative Care Service Delivery Plan (incorporating specialist palliative care, general palliative care and public health approaches to palliative care), including timelines to measure implementation targets and aligned with the following documents:
  - [Human Services Productivity Commission Report \(2018\)](#)
  - [Palliative Care Service Development Guidelines \(2018\)](#)
  - [National Palliative Care Standards \(2018\)](#)
  - [Queensland: An Aged Friendly Community strategic direction \(2016\)](#)
  - [Dying Well Report \(Grattan Institute, 2014\)](#)
  - [Government Response to Recommendations Health and Community Services Committee Palliative and community care in Queensland: towards person centred care \(Report No. 22\) \(2014\)](#)
  - National Palliative Care Strategy (expected to be released in 2018)
- Establishment of a statewide network for specialist palliative care services (inclusive of Queensland Health services, NGOs and private providers) to streamline service improvements.
- Embedding patient experience into service quality measures.
- Public and transparent reporting of services outputs and outcomes.
- Recommendation by the Department of Health that all specialist palliative care services and funded NGOs use the Palliative Care Outcomes Collaboration (PCOC) dataset to promote consistent data collection and language. This should extend to non-specialist services as the opportunity arises through the PCOC program.

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<sup>7</sup> *Palliative Care Australia (2018) Palliative Care Service Development Guidelines. Downloaded from [palliativecare.org.au/download/10889/](http://palliativecare.org.au/download/10889/) on April 1, 2018.*

**Question 3:**

*What types of palliative care services do you think will be required in your local area or across the state to meet future demand? Will different services be needed in the future to those provided today?*

*If you are a palliative care service provider, please provide an estimation of the expected service needs and service setting preferences in your local area over the next 5-10 years.*

Palliative care is a rapidly changing sector, responding to community and health needs. We predict this rapid change will continue over the next 10 years (in line with the ageing population<sup>8</sup>), while treatment options increase and with the growth of death and compassion literacy. The palliative care sector needs to be able to respond to these changing needs and deliver flexible, agile services to the right people, at the right time, in the right place. Our models should be based on:

- best practice holistic care
- population needs and growth corridors
- community awareness and development
- community demand and directed care

Equitable access underpins the requirement of a Queensland Integrated Palliative Care Service Delivery Plan. With a diverse population profile and vast geographical diversity, a comprehensive overview is required to ensure highest quality end of life care is available to all Queenslanders.

Accountability and transparency must be embedded in reporting at both local and statewide levels, including an annual community report to provide local community feedback opportunities. This creates a true patient centred service design, and ensures the dying person is at the core of all service delivery models.

**To meet future need, PCQ calls for local (HHS) planning to meet future needs of the Queensland community by:**

- Implementing more flexibility in palliative care models that facilitate early intervention and involvement of palliative care in serious illness multi-disciplinary team meetings.

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<sup>8</sup> *Queensland Government Population Projections to 2031: Local Government Areas, 2011 edition, Office of Economic and Statistically Research, Queensland Treasury*

- Ensuring that every community is formally supported by a specialist palliative care service, and each Hospital and Health Service has a specialist palliative care service.
- Increasing Palliative Care respite opportunities to prevent caregiver burnout and reduce care burden.
- Ensuring the *Palliative care support and advice service* PalAssist includes information for each HHS about all levels of local palliative care services, supports and contacts.
- Ensuring all residential aged care facilities are supported by specialist palliative care community services.
- Ensuring bereavement services are provided by all specialist palliative care services.
- Increasing home-based palliative care options (including home-based services and community dying option, with both hospice and residential aged care models).
- Utilise recommendations in the Productivity Commission Inquiry report into Human Service<sup>9</sup>.

**PCQ calls for either continued (substantive) funding for, or establishment of, the following statewide services to meet future need:**

**Bodies:**

- Palliative Care Queensland
- Centre for Palliative Care Research and Education
- Statewide Palliative Care Volunteer Support Service
- Centre for Community Engagement and Social Impact in Palliative and End of Life Care

**Strategies/Policies:**

- Queensland Integrated Palliative Care Service Delivery Plan (as detailed in Question 2), incorporating:
  - palliative care workforce planning strategy
    - *accepted key competencies across the professions and a means of developing those competencies*
  - Service Delivery Framework
    - *transparent and accepted benchmarks for service provision based on population need projections*

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<sup>9</sup> Productivity Commission, 2017, *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Report No. 85, Canberra.*



- *ensure the National Palliative Care Standards<sup>10</sup> are met by each Level 3 and 2 Specialist Palliative Care Service provider in Queensland.*
  - Community Engagement and Development Strategy (including patient experience)
    - *including social impact measures*
- Statewide communities of practice (CoP) to drive strategy, innovation, collaboration, knowledge sharing, leadership, implementation strategies and improvement measures
  - Statewide Specialist Palliative Care CoP
  - Rural and Remote Palliative Care CoP
  - Aboriginal and Torres Strait Islander Palliative Care CoP
  - Vulnerable Populations Palliative Care CoP
  - Home Based Palliative Care CoP
- Bi-Annual statewide palliative care report (inclusive of data from all palliative care service providers and projects) which is publicly available for the sector, policy leaders and local community members.

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<sup>10</sup> *Palliative Care Australia (2018) National Palliative Care Standards (Version 5) Downloaded from [palliativecare.org.au/download/10909/](http://palliativecare.org.au/download/10909/) on April 1 2018.*