
# 2020
# Palliative Care in Queensland Priorities

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PalliativeCare QUEENSLAND
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## Acknowledgements

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

This publication is an initiative of PCQ's Strategy and Policy Team. PCQ wish to thank all of our stakeholders who have given their valuable time and expertise to help guide the development of this publication. We greatly appreciate the contributions everyone has made in sharing experience, knowledge and time with us.


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## President's Foreword

On behalf of Palliative Care Queensland,
I am pleased to present the 2020 Palliative Care in Queensland Priorities.

There has never been a more critical time for the palliative care sector to set priorities. With the current Royal Commission into Aged Care Quality and Safety and the Queensland Parliamentary Inquiry into Aged Care, End-of-Life and Palliative Care, and Voluntary Assisted Dying (VAD), many Queenslanders fear the gaps in care and support they may encounter near the end of life.

As your peak body, PCQ brought together the Palliative Care in Queensland community in December 2019 to tackle these gaping needs. This document defines the priorities determined at that gathering.

On behalf of the State Council of Palliative Care Queensland, I commend this document to you. We hope these priorities will stimulate action. Please consider including these priorities in your organisational and strategic plans, thinking about how else you might influence the provision of improved palliative care, and working with us to transform palliative care in 2020.

**Mr. John Haberecht**
President
Palliative Care Queensland

## Background

**Palliative Care Queensland (PCQ) is an independent not-for-profit peak body with charitable status** representing the people who care for Queenslanders living with life-limiting conditions.

**Our belief**: The way we care for our dying is a significant indicator of our society's values

**Our mission**: Quality care at the end of life for all

**Our vision**: To hear Queensland community members say:

> "I live in a community where everybody recognises that we all have a role to play in supporting each other in times of loss, ageing, dying and grief. We are ready, willing and confident to have conversations about living, ageing, dying and grieving well, and to support each other in emotional and practical ways."

PCQ has been operating for more than 30 years, has over 300 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 key priorities are that all Queenslanders:

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

The Palliative Care in Queensland Program supports palliative care policy development and sector advocacy, as well as demonstrating the value of palliative care through awareness, engagement and capacity building initiatives.

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## How the 2020 Priorities were developed

The second Palliative Care in Queensland Annual Summit (Summit) was held on 02 December 2019 to share sector activities and to select priorities to help drive system transformation.

The Summit was attended by 100+ people from a diverse range of backgrounds and organisations. These included (but were not limited to) health professionals, social care organisations, aged care, peak bodies and academic institutions.

The morning session invited representatives from key peak bodies and government agencies to speak to their organisation's current palliative care initiatives, as well as the gaps and challenges they face. Speakers were also asked to share the priorities they would encourage the palliative care sector to tackle in 2020.

Next, six roundtables were held to bring together speakers, leaders, and participants to debate and choose the sector priorities in six key areas:

- Specialist palliative care
- Palliative care in aged care
- Palliative care workforce capacity building
- Public health approaches to palliative care
- Regional and rural palliative care
- Policy and strategy

The topics for the roundtables were selected from key priority areas identified by members and the palliative care sector throughout 2019.

Each of the roundtable discussions recommended priorities for the sector in 2020. These recommendations can be seen in the Appendix.

Following the event, priorities from the morning speakers and roundtable sessions were combined into one list. This list was sent to Summit attendees and PCQ members for feedback. The document was revised to reflect the received feedback, and then reviewed and approved by PCQ State Council on 19 February 2020.

# 2020

## PALLIATIVE CARE IN QUEENSLAND PRIORITIES

1

Ensure access to quality palliative care, and associated treatments and medicines, for all Queenslanders, irrespective of setting

2

Provide funding to promote palliative care along the spectrum (from diagnosis to bereavement) in any setting

3

Promote the public health palliative care approach and increase the community's awareness of palliative care

4

Redesign current health services to integrate palliative care

5

Ensure a workforce capable of delivering palliative care services

6

Advance palliative care services through research and innovation

# 2020 Palliative Care in Queensland Priorities

## 1 Priority 1. Ensure access to quality palliative care, and associated treatments and medicines, for all Queenslanders, irrespective of setting

a. Clarify the key quality measures and reporting strategies to improve access and quality of palliative care services across the state.

   This strategy should include measures around service delivery, operations and teams (potentially including FTEs, team and provider workloads, length of stay) and a transparent method to report outcomes.

b. Raise community expectations regarding standards for quality palliative care.

c. Build on social capital to develop sustainable volunteer programs for palliative care in aged care (home-based and facility-based) and the wider community (initially focus on rural and remote settings).

d. Invest in communication technologies that support collaborative practice between hospital-based specialist services and: (1) community-based[1] primary services; (2) rural and remote specialist services; and (3) community-based[1] specialist services.

e. Advocate for a system that provides a 24-hour support service for Queensland health care providers to access specialist advice.

f. Increase access to Indigenous Health Workers (with training in palliative care) and other supports for Aboriginal people and Torres Strait Islander people diagnosed with a life-limiting illness.

g. Plan for the future care needs of Queenslanders, especially with respect to demographic changes and increased rates of dementia and co-morbidities.

h. Develop bereavement services to increase reach across settings.

## 2 Priority 2: Provide funding to promote palliative care along the spectrum (from diagnosis to bereavement) in any setting

a. Target state funding to meet clear performance and quality criteria and goals for the place of palliative care services within the health system, beyond cancer services, with an emphasis in 2020 on indigenous populations, general medicine, aged care, paediatrics, and rural and remote health services.

b. Align reimbursement for General Practitioners who offer generalist palliative care services to patients in the community (including aged care facilities) with contemporary business models for medical services.

c. Extend funding to support advance care planning in primary care, community pharmacies, and financial planning services.

d. Invest in established specialist palliative care services for children to increase reach beyond the southeast Queensland region.

e. Ensure that funding is transparent, flexible, and fit for purpose. Ensure that palliative care funding is accountable and cannot be transferred to non-palliative care services.

*1. Community-based care includes services that are provided in a person's home.*

## 3 Priority 3. Promote the public health palliative care approach and increase the community's awareness of palliative care

a. Increase community awareness of death as a natural part of life by partnering with groups such as Queensland Compassionate Communities to deliver programs to start discussions for Queenslanders on what matters most around end of life, and bereavement seminars.

b. Map community assets and utilise existing social capital and partnerships to promote community engagement in the planning and provision of palliative care services.

c. Offer a once-only awareness campaign (with ongoing awareness information thereafter) for the Queensland community about what they can expect from high quality palliative care services and link this campaign to a call to action.

d. Improve access to community-based services and supports, e.g. with an annually updated list of community assets.

## 4 Priority 4. Redesign current health services to integrate palliative care

a. Use specialist palliative care services as hubs for generalist palliative care services, for integration into general medicine, paediatrics and rural and remote health services.

b. Improve access to specialist palliative care services in settings beyond hospital including community and residential aged care to support Queenslanders across the lifespan (including children) to die in a place of choice.

c. Improve transitions between facilities and services, e.g. learning from already established transition coordinators/nurse navigators in generalist palliative care service delivery.

d. Enhance the reach of palliative care in state-wide networks (cancer, older persons, dementia etc.) by advocating for the inclusion of palliative care as a standing agenda item and by including specialist palliative care representation as part of the membership.

e. Ensure palliative care is included in all hospital new builds and redesigns.

## 5 Priority 5. Ensure a workforce capable of delivering palliative care services

a. Ensure all Queensland Hospital and Health Services have (access to) a specialist palliative care service to meet the highest standard of Queensland's Clinical Services Capability Framework.

b. Establish a competency-based framework, with associated education and training, for generalist and specialist palliative care service providers.

c. Set targets to increase clinician access to palliative care education programs (online and other).

d. Create palliative care graduate positions (with an associated program of training and support) for clinicians based in geriatrics, general medicine, and paediatrics.

e. Develop educational resources that promote skills required for leadership, mentorship and teamwork, particularly across disciplinary boundaries and health service settings.

f. Examine mechanisms to share successful models of palliative care.

## 6 Priority 6. Advance palliative care services through research and innovation

a. Identify gaps in Queensland-based palliative care research and establish priorities for future work.

b. Foster industry, professional, community and researcher collaboratives to develop industry relevant innovation projects for Australian Research Council Linkage, National Health and Medical Research Partnership, and Advance Queensland Industry grant programs.

c. Examine the gaps in volunteer programs and review the exploratory work that has been done around training and volunteers in community and palliative care settings.

d. Encourage research to capture the innovations and outcomes arising from the application of the public health palliative care approach in Queensland.

## Appendix: Summary of Summit 2019 Roundtables

## **Specialist Palliative Care:** A Summary of Key Recommendations from 2019 Summit Roundtable One

1. Queenslanders with palliative care needs are better supported by specialist palliative care, clinical and non-clinical, formal and informal networks and services.
    a. Specialist palliative care services are supported to engage and partner with community capacity building activities and vice versa.
2. Queenslanders with palliative care needs are better supported by all health and care providers/services when and where they are needed, no matter who or how it is funded.
    a. Investigate and map models that enable specialist palliative care teams to be better integrated and accessed by broader health and care providers across Queensland.
    b. Ensure all Hospital and Health Services have specialist palliative care services, in line with cancer and other relevant health services in their Hospital and Health Services area (as specified in the Queensland's Clinical Services Capability Framework) and according to the Palliative Care Services Development Guidelines (2018, PCA).
    c. Enable all specialist palliative care services to provide 24-hour support to their linked community providers, which includes aged care and other residential care locations.
    d. Ensure specialist palliative care services are available in the home (including residential aged care) as well as inpatient settings, which may include telehealth and 'pop-up' models as determined by need and community consultation.
3. Queenslanders with palliative care needs and their families are able to transition between locations and care providers seamlessly, with access to clear and consistent information to enable informed decisions about their care and the options available to them.
    a. Increased communication and transparency within and between Health and Hospital Services and specialist palliative care teams regarding policy, models of care (referral) and funding.
        i. For example: Develop wrap-around palliative care packages for home-based care, which specialist palliative care services can deliver and flex to meet individual needs in a timely manner.
4. Demonstrate the value of palliative care in Queensland which includes access to specialist palliative care services, general practitioners and allied health professionals who provide generalist palliative care, and compassionate communities. Ensure awareness and engagement campaigns targeting consumers, carers, community and service providers have clear and consistent messaging with national campaigns so as to not increase confusion.

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## 2020 Palliative Care in Queensland Priorities

| 1 | 2 | 3 | 4 | 5 | 6 |
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## **Palliative Care in Aged Care:** A Summary of Key Recommendations from 2019 Summit Roundtable Two

1. Improve continuity across the care continuum, particularly in relation to transitions between home-based care to acute care to aged care (facility or home care).

2. Increase consumer and volunteer engagement.

    a. We need support to create engagement strategies and campaigns to target consumers and volunteers to be involved in palliative care in aged care (look at successful campaigns used around the world).

    b. Queenslanders need help to understand what palliative care is, and what it isn't. For their sake, we need to begin to have these conversations about palliative care much earlier.

3. Increase the number of early Advance Care Planning (ACP) discussions – at or before diagnosis.

    a. We need to collaborate with General Practitioners to recognise that we are not having discussions early enough and that ACP discussions are important early in diagnosis.

    b. We need to consider innovative ways to begin these discussions early – e.g. when children are in school, when you sign up for superannuation, when you enrol to vote.

    c. Perhaps we need to look at incentives, like tax breaks!

4. Ensure that aged care clients have access to both specialist palliative care services and generalist services.

    a. Use communication technologies to bridge the gap.

    b. Support mentoring on a local level, such as GP to GP.

5. Share successful models. Identify strengths in successful palliative care models and pilot these to other areas, particularly in relation to providing care for disadvantaged groups and sharing policies and procedures.

    a. Though there are many challenges (decentralised Hospital and Health services, a variety of agendas, the difficulties encouraging GPs to take on RACF patients), there are many successful models we can adapt for the Queensland context.

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## **Palliative Care Workforce Capacity Building:** A Summary of Key Recommendations from 2019 Summit Roundtable Three

1. Promote palliative care knowledge and skills within the whole of workforce – palliative care is everybody's business.
    a. Promote palliative care capabilities within undergraduate and entry to practice programs across medical, nursing and allied health.
    b. Advocate for Queensland Health to invest in new graduate pathways/positions in acute, RACF and community-based settings which explore palliative care roles.
    c. Include palliative care in mandatory and ongoing professional development.
    d. Sustain the workforce through positive culture and support (self-care).
2. Develop champions across all levels of service delivery to promote awareness and/or quality provision of palliative care.
    a. Support the paid and volunteer workforce to promote palliative care.
3. Ensure the workforce can work with multiple services (interagency negotiation, multiple funding sources) and resources to promote equitable care.
    a. Build a mentorship and supervision program led by palliative care services for their linked services.
    b. Support specialist palliative care services and health professionals to provide mentorship.
    c. Develop resource database inclusive of palliative care resources e.g. contact lists, training opportunities, help line.
    d. Use innovation and technology to promote access to palliative care.

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## **Public Health Palliative Care:** A Summary of Key Recommendations from 2019 Summit Roundtable Four

### A Public Health Perspective on Palliative Care

*"Death, dying, loss and care is everyone's responsibility. A public health approach to end of life care, views the community as an equal partner in the long and complex task of providing quality healthcare at the end of life."*[2]

We need a Public Health Palliative Care approach to better help Queenslanders with palliative care needs and their families.

That Public Health Palliative Care approach needs to be:

a. Underpinned by a state-wide Public Health Palliative Care strategy.

b. Informed by current and ongoing research and evaluation.

c. Incorporating specialist palliative care, generalist palliative care, compassionate communities and civic end-of-life care.

How do we go about this?

a. Promoting community engagement and partnerships between services and communities (including local government).

b. Mapping community assets and making this information widely available.

c. Strengthening existing volunteer training and networking opportunities.

As we go about this work, we will utilise Palliative Care Queensland's Queensland Compassionate Communities arm to act as an advocate, navigator and awareness raiser.

*2. Public Health Palliative Care International. http://phpci.info/ (accessed 19 February 2020).*

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## **Regional and Rural Palliative Care:** A Summary of Key Recommendations from 2019 Summit Roundtable Five

1. Acknowledge and support pre-existing social capital in rural and regional communities through volunteer opportunities.

    a. Promote, support and tap into pre-existing social capital in rural, remote and regional communities.

    b. Knowing what specific resources and services already exist – for the person with the life-limiting condition, for service providers and community members.

2. Bidirectional: Each rural and regional Hospital and Health Service's palliative care service should have a direct connection (education, clinical, telehealth) with an appropriate satellite (or regional) specialist palliative care service for support and service development.

3. Prioritise palliative care in regional and rural areas through flexible funding to provide the necessary infrastructure and service-level resources.

    a. Prioritise workforce development and service level resources (through partnerships in specialist palliative care) at a locally appropriate level.

    b. Prioritise palliative care in rural, remote and regional areas through sustainable and appropriate funding.

    c. Transparency and accountability for Hospital and Health Service palliative care funding.

4. Rural and remote community engagement and capacity building, to develop further and build on existing social capital to meet community identified needs.

5. Establish an interdisciplinary local, regional, rural and remote palliative care network in Queensland to build capability, capacity and improve standards of care.

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## **Policy and Strategy:** A Summary of Key Recommendations from 2019 Summit Roundtable Six

1. Many people don't know what good palliative care is or what good quality palliative care looks like.

    a. We need to tell the "good stories" about Queenslanders who have good experiences with palliative care and the positive impact this has had on them and their loved ones.

    b. We need community members to know what palliative care services they should be able to access so they can ask for and demand those services if/when they are not available.

2. We need to develop an awareness campaign for the community and health professions that is visible, simple and clear, that addresses the fears people have about ageing and dying, and shows Queenslanders the kind of care they "deserve". Palliative care is a recognised human right.

3. Language matters. As a sector, we need to agree on definitions and use consistent language. Health professionals and organisations use words like "palliative care" and "end of life" but their meanings are inconsistent. Once we have a common terminology, we can also educate the media and community.

4. As we raise awareness of palliative care, we also need to ensure that there is capacity to deliver the services to all Queenslanders, no matter where they live – to avoid adding angst and anxiety to the terminally ill person and their loved ones.

5. We need to ensure that palliative care services are accountable and have equitable funding.

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