

2022-2023 Palliative Care in Queensland Priorities



palliativecareqld.org.au

We are inclusive.

We celebrate multiple approaches and points of view. We believe diversity drives innovation and connects us closer to our members, clients and our communities. We're building a culture where difference is valued. We take a holistic approach. We foster both a top-down and grassroots approach. When we say Palliative Care is Everybody's Business, we mean everybody.

Acknowledgements

Our organisation acknowledges the Traditional Custodians of the lands and seas on which we live and work, and pays respect to Elders - past, present and emerging.

This publication is an initiative of Palliative Care Queensland's Policy Team. Palliative Care Queensland wish to thank all our staff who have supported the development of this document and 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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Background

About Palliative Care Queensland

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."

Palliative Care Queensland (PCQ) is a leading charity and independent peak body representing palliative care providers, consumers and their families and those with an interest in palliative care in Queensland.

PCQ was established in 1988 and is a membership-based organisation, supporting the individuals, families, carers, community members, as well as specialist and generalist health care professionals working with Queenslanders experiencing serious illness, dying, death and grief. Collectively, the PCQ membership body holds tremendous knowledge and wisdom about the challenges the sector faces and the opportunities those challenges can bring. PCQ is a founding member of Palliative Care Australia.

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





About Palliative Care Queensland's Annual Summit and Annual Palliative Care in Queensland Priorities publication

"PCQ recognises that there is limited resource in the palliative care sector therefore by identifying and publishing annual priorities for the sector we hope that we can help provide direction for those limited resources, thereby creating a collective effort focusing on specific priorities, focus areas and improvement areas."

- Shyla Mills, CEO Palliative Care Queensland

PCQ first hosted their Annual Summit in 2018. The purpose of this Summit was to bring together people with a key interest in Palliative Care in Queensland, to discuss learnings, build connections and identify sector priorities. The Annual Summit structure has adapted overtime but continues to include a forum and roundtables.

The Annual Palliative Care in Queensland Priorities publication was first published in 2019. The purpose of this document was to share the outcomes of the Summit and provide a tool for the Queensland Palliative Care sector to identify strategy, policy and actions for the following year. This document was originally focused on the calendar year but now aligns to the financial year which matches the way most service systems operate.



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How the 2022-23 Priorities were Developed

The Palliative Care Queensland Annual Summit

The Palliative Care Queensland Summit is an annual event that includes both a *State of the State* conference-style forum and a series of *Hot Topic roundtables*.

Over 150 people from a diverse range of backgrounds and organisations participated in these online activities. Participants included (but were not limited to): consumers, including those with personal experience in palliative care, a cross section of health professionals, including Palliative Care Specialists, General Practitioners, nursing and allied health representatives, social care and advocacy organisations, frontline aged care staff, nurses, medical providers and aged care provider representatives. Queensland peak bodies also participated, including representatives from the Queensland Compassionate Communities network. Academic experts and academic institutions were also represented.

State of the State Forum

The *State of the State* conference-style forum took place on the 17th of November 2021, where representatives from key state and national organisations described the challenges they faced in 2021 and the key priorities they recommend the palliative care sector could tackle in 2022-23.

Hot Topic Roundtables

Six virtual roundtables where then hosted between 30th of November and 2nd of December 2021. Topics included:

- 1. Specialist Palliative Care
- 2. Generalist Palliative Care
- 3. Public Health Palliative Care
- 4. Palliative Care for First Nations people
- 5. Palliative Care for people living in regional, rural and remote areas; and
- 6. Palliative Care for people experiencing homelessness

The topics for the roundtables were selected from key areas of interest identified by PCQ members and the palliative care sector, during consultations throughout 2021-22. Each of the roundtable discussions recommended improvements, the improvements were sorted by the PCQ policy team and seven key improvement areas are shared in section two of this report.

Priorities theming, ranking and finalisation

The findings from these two activities were analysed by the PCQ policy team and a draft version of the 2022-23 Palliative Care in Queensland Priorities was created. This draft version was then sent to all Summit attendees and PCQ members for feedback and ranking. The document was revised to reflect feedback and then reviewed and approved by the PCQ Board in May 2022.





SECTION 1: 2022-23 PALLIATIVE CARE IN QUEENSLAND PRIORITIES

2022-23 PALLIATIVE CARE IN QUEENSLAND PRIORITIES





PRIORITY 1 | WORKFORCE: Strengthen the whole sector workforce capacity in palliative care

Key Focus Areas for this Priority

- Expand the current palliative care workforce plan to include the whole sector workforce (both public and private, and both specialist and generalist), including nurses, doctors, allied health professionals, counsellors, spiritual carers, grief and bereavement support, administration support etc.
- Initiate succession planning, back-fill and improving navigation roles for major and minor services throughout the palliative care journey so that patients and families can be followed-up and not get lost in the system.
- Support innovative models of care to satisfy increasing demand for palliative care, especially in challenging situations, such as a pandemic.
- Develop sector strategies to increase staff competencies and capabilities in palliative care, including cultural training, psychosocial care and self-care.
- Increase primary care involvement and support for palliative care in relation to aged care, disability and generalist palliative care in the community.
- Advocate to deepen palliative care education in undergraduate/graduate settings as well as to support and upskill current staff with access to high quality educational programs, tools and mentoring opportunities.



PRIORITY 2 | SECTOR FUNDING: Fund and support palliative care to improve access, equity and transparency across the sector

Key Focus Areas for this Priority

- Provide equity in funding in remote, rural and regional areas to the parity of access in metropolitan areas, to ensure that care is coordinated (e.g., primary care, acute care, aged care and all other services in the community). Remuneration should be appropriate to the services provided.
- Increase the base investment to the whole palliative care sector, including service delivery and capacity building, administration support and digital health initiatives.
- Invest in increasing workforce capacity and capability through training and development, by improving education to address the specific palliative care needs such as explicit clinical skills.
- Build organisational capacity and capability of the existing palliative care systems to connect with people of all ages and their families, for early and continuous access to palliative care services, rather than last stage intake which can exacerbate the consequences of grief and trauma for the family.
- Fund system improvements to build community capacity, including policy, advocacy and awareness-raising programs, because palliative care is for all ages and stages.
- Promote funding models (private and public funding) that adapt to changing palliative care needs and reduce the burden on the public system, with particular focus on community (home) based palliative care.





PRIORITY 3 | HOLISTIC AND INCLUSIVE CARE: Strategically increase sector capacity and capability to provide access to holistic care and inclusive care

Key Focus Areas for this Priority

- Ensure all palliative care services include the provision of culturally appropriate psychological, spiritual and bereavement care to people. This is core to the definition of palliative care.
- Offer holistic care and provide assistance to family members during their transition across services throughout their entire journey (from diagnosis through to bereavement).
- Improve care for First Nations people, engaging in dialogue and collaboration to redesign existing services to address inequities, especially regarding holistic palliative care in place of choice and the ability to die on country.
- Facilitate navigation across Culturally And Linguistically Diverse (CALD) communities and different societies of the state to change the focus of palliative care, which is not only about death but also about living.
- Focus on sector capacity building and improvements in relation to care for underserved population groups including First Nations, CALD, homeless, LGBTIQ+, prisoners and those without family or carer support.
- Close the gap and reduce the variation in the provision of palliative care services by prioritising First Nations-led and community-led palliative care services.

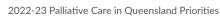


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PRIORITY 4 | REMOTE, RURAL AND REGIONAL ACCESS: Ensure equity and access of palliative care services; narrow the gap between remote, rural and regional areas of Queensland

Key Focus Areas for this Priority

- Address the shortage of palliative care professionals who support people in the community, prioritising remote, rural and regional areas where the scarcity of health care workers is critical and gravely affects the delivery of quality palliative care.
- Develop solutions to promote equal access to palliative care in remote, rural and regional areas of Queensland as well as building community capacity within a centralised model.
- Overcome barriers to promote access and equity by deploying services and professionals that can assist in navigating diagnosis, treatment and bereavement care and enable culturally appropriate palliative and psychological support to the remote, rural and regional communities across Queensland.
- Improve both telehealth services (increase and upgrade technology) and intensify specialist palliative care staff availability in community settings, so 24/7 service delivery is strengthened.
- Develop a more aligned and congruent strategy to support service models that include remote, rural and regional coverage options.
- Strengthen relationships and partnerships between different palliative care sectors (clinical, non-clinical, specialist, generalist, public, private) and population groups.





PRIORITY 5 COMMUNITY ENGAGEMENT: Improve and increase community awareness, engagement and partnerships

Key Focus Areas for this Priority

- Work with the community to understand information and access needs to assist them to navigate and engage in early palliative care conversations with people and families so that the community can access information, plan and manage symptoms and supports from early stages of disease.
- Overcome existing communication barries by promoting conversations around serious illness, dying, death and grief to increase compassion and death literacy, promotion of advance care planning and palliative care, and improve early access to palliative care.
- Increase the general public awareness and knowledge about self-managing grief (non-complex grief) as well as strengthen family support teams to facilitate communication channels within and across families in neighbourhoods to share their bereavement experiences and have a voice.
- Develop community engagement strategies to increase community competencies and capabilities in palliative care (including cultural awareness, bereavement care and self-care).
- Expand volunteering in generalist and specialist palliative care services by initiating programs that identify and train community volunteers who can: champion palliative care in their neighbourhoods, build compassionate communities that provide practical help to those who are dying and their carers, and link people with existing services.
- Widen and improve compassionate communities through the development and implementation of asset mapping, auditing and service tools, to maximise the appropriateness of services.



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PRIORITY 6 INNOVATION AND RESEARCH: Advance and showcase research, innovation and sector improvements in palliative care

Key Focus Areas for this Priority

- Improve current tools and techniques to measure quality service provision so that people's experiences of wellbeing can be better monitored and understood by palliative care health services.
- Provide funding for new research opportunities, build a palliative care research workforce and implement quality improvement of systems and practices related to end-of-life, for gathering high-quality research for reporting and evaluating new evidence generated in Queensland.
- Improve research and data collection for rigorous and transparent evaluation of existing palliative care services and programs (examining quality, effectiveness, outcomes, social impacts and cost-benefits).
- Create a strategy to advance research in Queensland that considers the full spectrum of care with increased advocacy for homeless people and prisoners, whose population is majority First Nations.
- Implement innovative results of research in palliative care for continuous improvement of services delivery in order to support the communities in the state.
- Create and build partnerships with allies in policy, practice and research.



Call to Action: Disseminating and Activating the 2022-23 Priorities

The 2022-23 Palliative Care in Queensland Priorities were created by the sector, for the sector.

These priorities were developed following a robust process of consultation. They provide direction for the sector that supports much needed transformation of Queensland's palliative care system.

To become involved in promoting the priorities, please consider the following possibilities for action:



Promote through your social media channels using #22-23QPallCarePriorities and tag in PCQ.



facebook.com/ PalliativeCareQueensland



linkedin.com/ palliative-care-queensland



twitter.com/ palliativecareq



instagram.com/ palliativecareq





SECTION 2: 2022-23 HOT TOPIC KEY IMPROVEMENT AREAS IDENTIFIED AT THE PCQ SUMMIT 2021 ROUNDTABLES

2022-23 Hot Topic Key Improvement Areas Identified at the PCQ Summit 2021 Roundtables





2022-23 Key Improvement Areas Hot Topic: Specialist Palliative Care

A Summary of Key Improvement Areas identified during this roundtable:

- Improve funding to strengthen the workforce in the community instead of going to non-government organisations.
- Improve and expand awareness of palliative care and the availability of resources in communities.
- Improve fundraising strategies in order to raise funds from different sources other than the government:
 - Develop a fundraising week that is separate from awareness-raising activities.
 - Facilitate fundraising education aimed at hospices and palliative services (there are some examples in the UK).
- Improve data and information about the different palliative care services' gaps.
- Develop succession planning for more smaller services.
- Improve collaboration at the local and state level as the health care system is decentralised.
- Improve communication between the different palliative care teams and services.

2022-23 Hot Topic Key Improvement Areas Identified at the PCQ Summit 2021 Roundtables

Specialist <u>Palliative Ca</u>re

Generalist Palliative Care Public Health Palliative Care Palliative Care for First Nations people Palliative Care for people living in regional, rural and remote areas





2022-23 Key Improvement Areas Hot Topic: Generalist Palliative Care

A Summary of Key Improvement Areas identified during this roundtable:

- Address the gap between aged care, disability care and palliative care.
- Develop strategies to increase responsibility and accountability for palliative care service delivery across different domains.
- Improve the workforce in generalist palliative care. There is a need for 24/7 on-the-ground generalist nursing for patients and family support throughout the state, including rural and remote QLD:
 - Increase generalist nursing and GP/nurse practitioner support for recurrent home visits.
- Develop consistency in palliative care services across different areas, mainly in rural and remote areas:
 - Integrate services as there is a fragmentation of palliative care services delivered in the state.
- Increase awareness among the providers of specific palliative care projects and tools and encourage them to promote these programs in the community.
- Develop digital strategies for communication across all palliative care providers:
 - Improve telehealth and technological tools to deliver palliative care services.
- Increase the general public's knowledge of palliative care to improve bereavement support.

2022-23 Hot Topic Key Improvement Areas Identified at the PCQ Summit 2021 Roundtables

Specialist Palliative Care Generalist Palliative Care Public Health Palliative Care Palliative Care for First Nations people Palliative Care for people living in regional, rural and remote areas





2022-23 Key Improvement Areas Hot Topic: Public Health Palliative Care

A Summary of Key Improvement Areas identified during this roundtable:

- Strengthen volunteer models throughout Queensland.
- Educate palliative care staff to provide community education, mapping community and service navigation.
- Redirect focus of palliative care as it is not about dying but about living the time you have left.
- Create a space for community and consumers to share their voice.
- Improve community capacity building, such as resources in the community, education so the community can respond and using community education as an early intervention.
- Observe and take examples of models that have been developed internationally.
- Improve the data collection system to relevant public health or population measures, such as CALD populations or social determinates of health.

2022-23 Hot Topic Key Improvement Areas Identified at the PCQ Summit 2021 Roundtables

 Specialist Palliative Care
 Generalist Palliative Care
 Public Health Palliative Care
 Palliative Care for First Nations people
 Palliative Care for people living in regional, rural and remote areas
 Palliative Care





2022-23 Key Improvement Areas Hot Topic: Palliative Care for First Nations people

A Summary of Key Improvement Areas identified during this roundtable:

- Integrate ongoing consideration of the Indigenous communities' perspectives on palliative care into systems.
- Develop culturally appropriate and trauma informed models.
- Increase Indigenous workforce in palliative care, as currently, the majority is non-indigenous.
- Strengthen the community-based services delivered to Indigenous communities as their priority is to return to country:
 - Consider return to country and re-establish the bonds with elders as quality measures.
- Focus on advocacy around housing, education, prison and homeless issues as these are contributing factors for First Nations people.
- Develop and support compassionate community initiatives for First Nations people.
- Improve connection between social, cultural and health topics i.e. loss of housing, kinship and financial struggles need to be considered. Issues don't exist in isolation.

2022-23 Hot Topic Key Improvement Areas Identified at the PCQ Summit 2021 Roundtables

Specialist Palliative Care Generalist Palliative Care Public Health Palliative Care Palliative Care for First Nations people Palliative Care for people living in regional, rural and remote areas





2022-23 Key Improvement Areas Hot Topic: Palliative Care for people living in regional, rural and remote areas

A Summary of Key Improvement Areas identified during this roundtable:

- Increase availability of providers to support people 24 hours a day, in order to decrease admissions to emergency departments.
- Increase palliative care services on islands and other remote communities as it is challenging to find respite services and there are limited (if any) hospital beds.
- Ensure accountability and transparency of allocation of funding and resources:
 - Integrate services to avoid funding going to particular pockets.
 - Strengthen relationships between different areas; non-government organisations, hospital services, community groups.
 - Identify private health funding opportunities.
- Develop more aligned and congruent strategies and service models that include rural and remote coverage options.
- Improve communication between different palliative care services.
- Address the shortage of professionals that support people in the community.
- Build community capacity within a centralised model.

2022-23 Hot Topic Key Improvement Areas Identified at the PCQ Summit 2021 Roundtables

Specialist Palliative Care Generalist Palliative Care Public Health Palliative Care Palliative Care for First Nations people Palliative Care for people living in regional, rural and remote areas





2022-23 Key Improvement Areas Hot Topic: Palliative Care for people experiencing homelessness

A Summary of Key Improvement Areas identified during this roundtable:

- Ensure there are accommodation options for homeless people when they leave hospitals (consider the approach that was used during the COVID-19 lock downs).
- Strengthen compassionate communities' strategies as families living in the streets receive support from nurses, counsellors and their communities that are part of compassionate communities.
- Strengthen the connection between correctional services and palliative care services:
 - Support the prisons pathway as the system is now trying to ensure that people who have a palliative care diagnosis are appropriately supported when released.
 - Develop self-care strategies for workers in prisons, as inmates suffering from a life-limiting condition can be very confronting for them. There are some young support workers, so self-care planning is needed.
- Understand the diversity in homelessness and develop strategies for people dying in cars, couch surfing or in hotels/hostels/tents with no support from families.
- Improve reporting of deaths of homeless people as currently it is underreported:
 - Strengthen relationships and liaison with the police force and increase the collection of data on deaths of people experiencing homelessness.
- Improve spiritual support for people experiencing homelessness. Spiritual care is a critical domain of palliative care. Many people are not religious, but their spirituality, purpose and meaning-making is important.
- Improve early access referrals of people experiencing homelessness, to specialist palliative care:
 - Early referrals to palliative care can enable stronger relationships and trust, particularly enhancing pain relief, social connectedness and meaning.

2022-23 Hot Topic Key Improvement Areas Identified at the PCQ Summit 2021 Roundtables

Specialist Palliative Care Generalist Palliative Care Public Health Palliative Care Palliative Care for First Nations people Palliative Care for people living in regional, rural and remote areas





Call to Action: Disseminating and Activating the 2022-23 Hot Topic Key Improvement Areas

The 2022-23 Palliative Care in Queensland Hot Topic Key Improvement Areas were created by the sector, for the sector.

These Key Improvement Areas provide guidance for individuals, organisations or policy makers working in these relevant areas.

Strategies for teams activating these include:



Download and share the relevant Hot Topic Key Improvement Area handout with your team/networks.



Host a team/network meeting to discuss the relevant Hot Topic Key Improvement Areas and identify what actions you could implement to drive these forward.



Integrate actions into your Quality Improvement or activity plans for 2022-23.



Share your actions/improvements with your networks, on social media and/or with Palliative Care Queensland.

Promote through your social media channels using #22-23QPallCarePriorities and tag in PCQ.



facebook.com/ PalliativeCareQueensland



linkedin.com/ palliative-care-queensland



twitter.com/ palliativecareq



instagram.com/ palliativecareq



Notes	

Palliative Care Queensland's policy guiding principles



Support Palliative Care Queensland to continue to host the Annual Summit and develop the Annual Palliative Care in Queensland Priorities

Sponsor our Annual Palliative Care in Queensland Summit



Contact our marketing team to discuss sponsorship opportunities for our Annual Summit event: **partnerships@palliativecareqld.org.au**

Make a tax-deductible donation to Palliative Care Queensland



All donations over \$2 are tax deductible. Please help PCQ to educate and advocate for Queenslanders to live, die and grieve well.

Donations can be made at www.palliativecareqld.org.au/donation

Donations can also be made by **cheque**, **postal order or direct transfer** (BSB 064–012 Account 1014 6267 with your full name as reference. Please email accounts@palliativecareqld.org.au if you would like a receipt emailed for your donation).

Become a member of Palliative Care Queensland



Membership of Palliative Care Queensland is available to individuals or organisations who have an interest in palliative care in Queensland.

Individual membership is \$75/year

Organisational membership is \$300/year

Join today: www.palliativecareqld.org.au/pcqmembership



palliativecareqld.org.au





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b palliativecareqld.org.au

