



# 2021 Palliative Care in Queensland Priorities

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*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 PCQ's Strategy, Policy and Social Impact 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 2021 Palliative Care in Queensland Priorities.

This year, 2021 will be a watershed time for palliative care in Queensland. Given the ongoing impact of COVID-19, the results of the 2020 Queensland Election and the related funding commitments made to palliative care, reports from the Aged Care Royal Commission, along with Queensland's legislative consideration of Voluntary Assisted Dying (VAD), it is imperative that we come together as a sector to promote and activate selected priorities to transform palliative care.

The priorities in this document reflect the findings arising from a sector briefing, an online poll, and six virtual roundtables. These three sets of online consultations were organised as part of our Annual Summit held in November and December 2020 by Palliative Care Queensland, which brought together consumers, representatives from peak bodies in Queensland and Australia, as well as many healthcare practitioners.

These groups gathered to review the challenges the sector faced in 2020, and to put forward priorities the sector could consider tackling in 2021.

On behalf of the State Council of Palliative Care Queensland, we commend these priorities to you. We ask you to consider disseminating and activating them through your various networks and social media. Queenslanders desperately need us to improve quality care for people experiencing serious illness, dying, death and grief, and we hope that enacting the priorities and key focus areas suggested in this document will bring us closer to providing the kind of palliative care that should be available to every Queenslander.

Thank you for working with us to transform palliative care.

A handwritten signature in black ink, appearing to read 'Marg Adams'.

**Marg Adams**  
President  
Palliative Care Queensland

## 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

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 2021 Priorities were Developed

The Palliative Care in Queensland Summit is an annual event that is usually held in person to identify palliative care sector priorities for the coming calendar year. Due to COVID-19, we restructured the 2020 Summit as an online series of events.

Over 180 people from a diverse range of backgrounds and organisations participated in these three 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 Communiites network. Academic experts and academic institutions were also represented.

The online Summit 2020 activities included:

1. **A Sector Briefing** that took place on the 18th of November, where representatives from key state and national organisations described the challenges they faced in 2020, and the key priorities they recommend the palliative care sector could tackle in 2021.
2. **A Sector Poll** where respondents identified their top priorities for 10 different topics. Sector Poll topics were selected based on key areas of interest identified in the 2020 priorities, including asking respondents to reflect on the influence of events the sector experienced in 2020, including COVID-19.
3. **Six Virtual Roundtables** where topics included:
  - a. Specialist Palliative Care
  - b. Palliative Care for Aboriginal & Torres Strait Islander People
  - c. Palliative Care in Generalist & Primary Care
  - d. Palliative Care in Regional and Rural Areas
  - e. Palliative Care in Aged Care
  - f. Public Health Palliative Care

The topics for the roundtables were selected from key priority areas identified by members and the palliative care sector throughout 2020. Each of the roundtable discussions recommended priorities for the sector in 2021. A summary of these recommendations can be found in the Key Improvement Areas.

The findings from these three activities were analysed by PCQ State Council and a staff working group, and a draft version of the Palliative Care in Queensland Priorities for 2021 was created. This draft version was then 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 in March 2021.

**2021 PALLIATIVE CARE IN  
QUEENSLAND PRIORITIES**

# 2021 PALLIATIVE CARE IN QUEENSLAND PRIORITIES



# 1

## **PRIORITY 1: Fund and support palliative care to improve sector effectiveness and quality<sup>1</sup>**

### **Key Focus Areas for this Priority**

- Increase the base investment\* to palliative care service delivery including palliative care home packages, the specialist palliative care workforce, other targeted palliative care programs, and telehealth and other communication technology initiatives.
- Fund\* system improvements to build community capacity, including policy and awareness raising, workforce training and development, database registries, and compassionate communities.
- Where there is capacity, position general practitioners as central to the palliative care continuum wherever their patients are, to ensure that care is coordinated (e.g., primary care, acute care, aged care and all other services in community). Remuneration should be appropriate to the services provided.
- Promote funding models that are reflective of the needs of the patient and carer trajectory, designed with flexibility to adapt to changing palliative care needs and all diagnoses (for example, renal, cardiac, respiratory, neurodegenerative).
- Ensure that funding for palliative care services in Queensland is fit for purpose, transparent, accountable, tied to palliative care budgets (where funds allocated to palliative care cannot be transferred to other areas of the health system) and recurrent and sustained.

*\* All funding for palliative care initiatives must be tied, accountable and transparent, meaning that funding allocated to palliative care cannot be transferred to other areas of the health system.*

## 2

# **PRIORITY 2: Redesign services to ensure equitable and holistic access along the entire palliative care journey**

## **Key Focus Areas for this Priority**

- Improve care for Aboriginal and Torres Strait Islander peoples, engaging in dialogue and collaboration to redesign services that address profound inequities, especially regarding holistic palliative care in place of choice and the ability to die on country. Support and train the Aboriginal and Torres Strait Islander workforce and build the cultural competency of the entire palliative care workforce.
- Plan for whole of person care, so that patients and carers can easily access necessary medical, nursing and interdisciplinary care that is culturally appropriate and includes psychosocial, spiritual and bereavement care. This care should be offered along with curative treatments.
- Strategically expand palliative care services for people living in regional and rural areas, focusing on multidisciplinary generalist and specialist services that can provide 24-hour support through local and statewide services (enhanced by communication technologies like telehealth).
- Restructure and expand person-centred services for all ages and stages, so that patients, carers and their circles of care can find early access to the supports they need for the entire palliative care journey, from diagnosis to bereavement, and for all populations from in-utero to geriatric. Collaborate with government and non-government services (including hospices) at all levels of policy creation and service planning.
- Provide services and supports that enable dying and death at place of choice for every Queenslanders.

# 3

## **PRIORITY 3: Work with the community (through the philosophy of public health palliative care) to increase awareness, engagement and partnerships**

### **Key Focus Areas for this Priority**

- Change the culture and promote conversations around serious illness, dying, death and grief to increase death literacy, promotion of advance care planning and to improve early access to palliative care.
- Amplify awareness and education initiatives so that Queenslanders understand exactly what palliative care is, how it can help and so they know how to navigate the palliative care support system from diagnosis to bereavement.
- Initiate 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. Expand volunteering in generalist and specialist palliative care services.
- In the spirit of 'nothing about me, without me,' engage and collaborate with consumers and carers in service development planning and new palliative care initiatives.
- Map assets and social capital to further the reach of palliative care through asset hunting and partnership and engagement building between services, civic community and social networks (including Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse communities).

# 4

## **PRIORITY 4: Build capacity in the palliative care health workforce to ensure competency, capability and appropriate staffing**

### **Key Focus Areas for this Priority**

- Work with regulatory bodies (including medicine, nursing, allied health, pharmacy and paramedicine) to ensure palliative care is reflected in competency standards for all health care practitioners.
- Develop sector strategies to increase workforce competencies and capabilities in palliative care (including cultural training, psychosocial care and self-care). Advocate to deepen palliative care education in undergraduate/graduate settings, and to support and upskill current workforce with access to high quality educational programs, tools and mentoring opportunities. Recognise the important role of multidisciplinary professionals.
- Encourage all Queensland Hospital and Health Services (HHS) to ensure their Clinical Services Capability Framework (CSCF) Palliative Care Service Levels are equal to their highest facility CSCF Level. Fund each HHS palliative care workforce to that level.
- Evaluate the ratios and skill mix of palliative care staff to patients (current state as well as future projected need) in Queensland against recommended practice standards in all care settings. Create a plan to increase and retain the palliative care workforce to ensure capability and stability of palliative care services in both metro and regional and rural areas.
- Create a flexible workforce that is responsive to patients and carers in a timely manner, where and when help is needed, especially in regional and rural settings. Ensure that the specialist workforce is supported to provide telehealth outreach to those community-based services without local specialist palliative care.

<sup>2</sup> Queensland Health uses the CSCF in each HHS to determine minimum capability criteria for service planning and delivery

# 5

## ***PRIORITY 5: Advance and showcase research, innovation and sector improvements in palliative care***

### **Key Focus Areas for this Priority**

- Identify gaps in palliative care research and create a strategy to advance research in Queensland that considers the full spectrum of care.

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- Showcase research-based and practice-based innovation, linking innovators with service providers to encourage appropriate scale-up.

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- Continue developing Queensland's palliative care communities of practice to support innovation and quality improvement.

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- Set up a data registry system that includes all palliative care service providers to map palliative care team operations and service delivery, with metrics tracking outputs, outcomes, access/capacity and quality.

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- Promote the need for rigorous evaluation of palliative care services and programs, examining quality, effectiveness, outcomes, social impacts and cost-benefits.

## **PRIORITY 6: Promote the role of palliative care in emerging issues, including disaster planning and the deliberation on Voluntary Assisted Dying (VAD) in Queensland**

### **Key Focus Areas for this Priority**

- When creating Queensland disaster plans (flood, fire and general disasters), ensure that palliative care is included in the planning, response and recovery phases. Embed palliative care in pandemic disaster planning, response and recovery, reflecting on state, national and international lessons learned to accelerate system reform.
- When changes in funding, service systems or policy result in decreased services to palliative care patients (for example, nursing funding to patients under age 65), advocate for a rapid system response so that patients don't experience gaps in service delivery.
- As Queensland continues further discourse on VAD, educate Queenslanders on the distinction between VAD and palliative care, the facts and realities of a good death and the role of palliative care, and the system reform required to appropriately support Queenslanders with the levels of palliative care they need.
- Provide support and promote self-care to the palliative sector (including generalists and specialists) during the deliberation on VAD as palliative care staff respond to the VAD inquiries that arise, and as they address misunderstandings about VAD and its distinction from palliative care.
- If VAD is to be implemented in Queensland, work with the legal and healthcare community (including peak bodies) to make clear funding and service delivery distinctions between palliative care and VAD (one choice does not exclude the other). Create opportunities for dialogue regarding how the palliative care sector will interact with those who offer and receive VAD, and the families needing bereavement care.

# Call to Action: Disseminating and Activating the 2021 Priorities

The 2021 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:

 <b>Individual Actions</b>	 <b>Organisational Actions</b>	 <b>Government Actions</b>
<ul style="list-style-type: none"><li>• Engage your personal networks, local community and community groups</li></ul> <hr/> <ul style="list-style-type: none"><li>• Talk to your local MP and local Council</li></ul>	<ul style="list-style-type: none"><li>• Include the priorities in your organisational strategic and operational plans</li></ul> <hr/> <ul style="list-style-type: none"><li>• Create working groups to enact the priorities</li></ul>	<ul style="list-style-type: none"><li>• Make the case for palliative care system improvements in the legislature and in committee work</li></ul> <hr/> <ul style="list-style-type: none"><li>• Use the priorities to guide government actions and priorities</li></ul>

Promote through your social media channels using **#2021QPallCarePriorities**.

If you would like more information on the case for palliative care:

- ***Palliative Care in Queensland Requirements for New Investment to Transform Care***  
<https://palliativecareqld.org.au/publications-resources>
- ***2021-22 Pre-Budget Submission Queensland***  
<https://palliativecareqld.org.au/positionstatements>

**KEY IMPROVEMENT AREAS  
IDENTIFIED AT THE  
PALLIATIVE CARE IN  
QUEENSLAND SUMMIT  
2020 ROUNDTABLES**

# Key Improvement Areas identified at the Palliative Care in Queensland Summit 2020 Roundtables

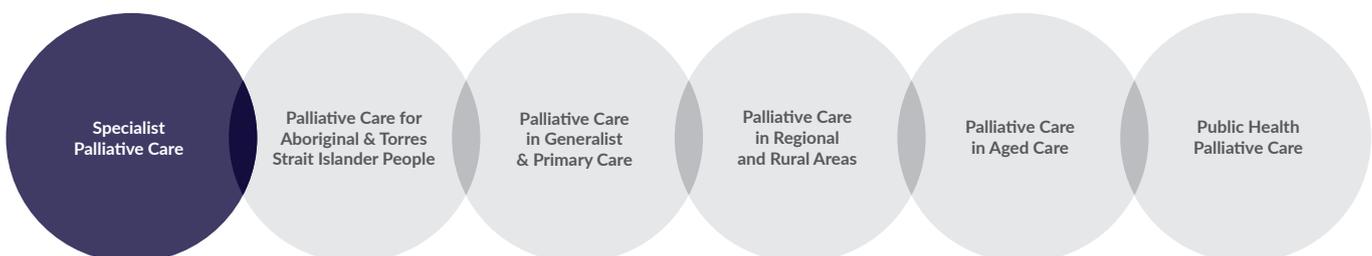


# 2020 Roundtable on Specialist Palliative Care

## A Summary of Key Improvement Areas

- Expand specialist palliative care workforce (and the correlating system supports) within specialist palliative care teams.
- Increase options for people to die at home including community packages for palliative care (such as Last Days Packages<sup>3</sup>).
- Improve strategic collaborations across the state between palliative care service providers.
- Increase specialist palliative care options for: First Nations people, for those in regional and rural settings (including telehealth), as well as for renal, cardiac, neurodegenerative and other life-limiting diseases.
- Improve transparency and accountability of palliative care funding in Queensland.

Key Improvement Areas identified at the Palliative Care in Queensland Summit 2020 Roundtables



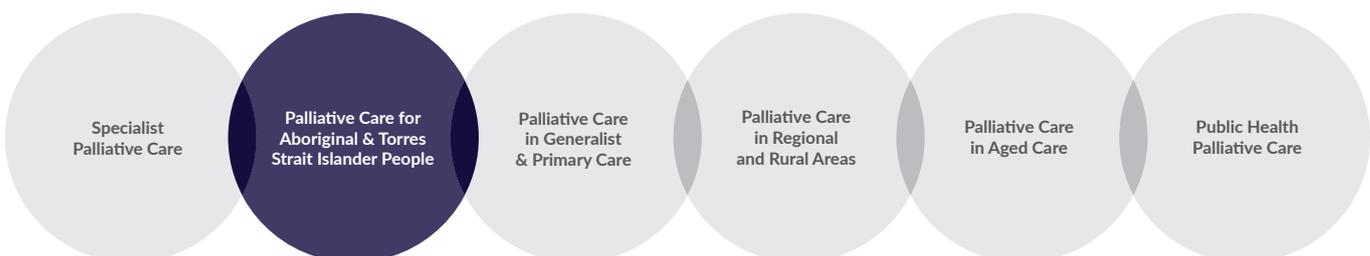
<sup>3</sup> Palliative Care Queensland (2020). Palliative Care in Queensland: Requirements for New Investment to Transform Care. Published on website: [www.palliativecareqld.org.au](http://www.palliativecareqld.org.au)

# 2020 Roundtable on Palliative Care for Aboriginal & Torres Strait Islander Peoples

## A Summary of Key Improvement Areas

- Increase supports for Aboriginal and Torres Strait Islander peoples to facilitate dying on country. Enhance HHS, state and commonwealth policies to provide support for the cultural aspects of dying, death and grief, acknowledging the cultural variance between communities, and providing clear information around funding where travel outside of one's community is needed.
- Build on Aboriginal and Torres Strait Islander workforce capacity and increase the opportunities to work within their communities.
- Ensure health services deliver culturally appropriate palliative care. Make cultural safety and trauma informed training mandatory. Redesign clinical units to support visitor numbers and needs, food storage and other cultural needs.
- Work with communities (they have the answers) through consultation and raise awareness of palliative care.
- Activate the community to influence government and services with the community voice. Work with Community Controlled Health Organisations to redesign palliative care services, including linking with other like-minded organisations.

Key Improvement Areas identified at the Palliative Care in Queensland Summit 2020 Roundtables

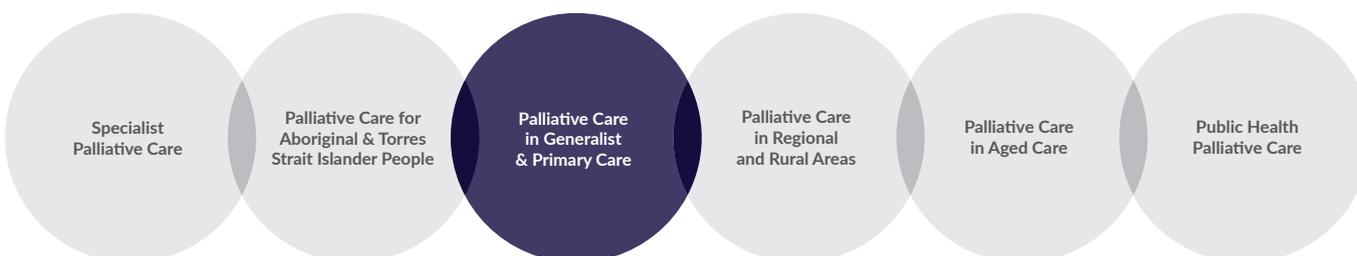


# 2020 Roundtable on Palliative Care in Generalist & Primary Care

## A Summary of Key Improvement Areas

- Strengthen the coordination of care between care settings (i.e., hospitals, GPs and community palliative care providers and networks). Empower GPs to coordinate their patients' care in community (including aged care) and to ensure the flow of information about patients across multiple settings. Support GPs to begin the conversations about care and care coordination early in the palliative care journey.
- Increase primary care funding, including appropriate remuneration and resourcing to enable primary care providers to respond to patients and carers' needs (particularly in their home).
- Map generalist and primary palliative care services to assist with system navigation, coordination and integration of patient care throughout the palliative care journey (i.e., from diagnosis to bereavement).
- Fund generalist and primary care services and supports to be rapidly responsive and mobile to patient care needs (such as Last Days Packages<sup>4</sup>).
- Equip and train frontline health staff to understand the diverse range of palliative care needs, and to ask their patients what matters most (i.e., advance care planning and care planning).

Key Improvement Areas identified at the Palliative Care in Queensland Summit 2020 Roundtables



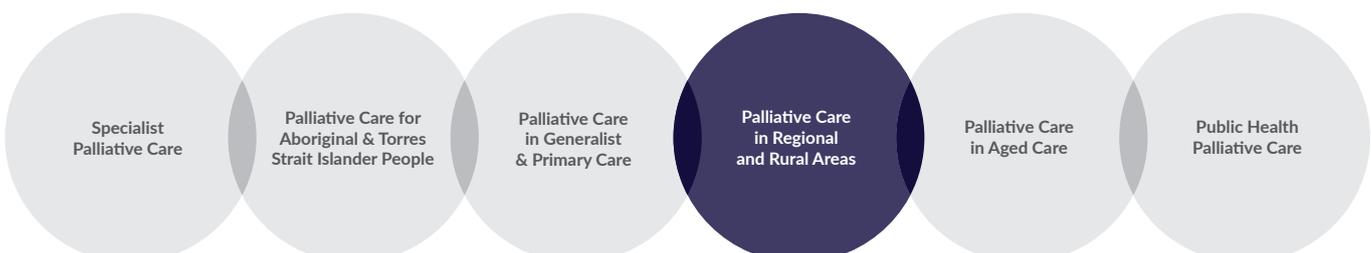
<sup>4</sup> Palliative Care Queensland (2020). Palliative Care in Queensland: Requirements for New Investment to Transform Care. Published on website: [www.palliativecareqld.org.au](http://www.palliativecareqld.org.au)

# 2020 Roundtable on Palliative Care in Regional and Rural Areas

## A Summary of Key Improvement Areas

- Map the gaps that prevent people from being able to return to regional and rural areas for their palliative care journey. Fund and support initiatives so that people have increased choices.
- Develop an integrated and useable structure across HHS palliative care services that is easy to navigate for patients, carers and health care professionals.
- Ensure adequate and sustainable funding for regional and rural palliative care services to enable a stable and skilled local workforce with flexible models of support (on the ground, telehealth and other innovations).
- Increase carer and family access to quality care and holistic supports that are equitable across regional and rural HHS areas.
- Ensure rapid access to appropriate palliative care personnel and supports (including medicines and equipment) in regional and rural areas.

Key Improvement Areas identified at the Palliative Care in Queensland Summit 2020 Roundtables

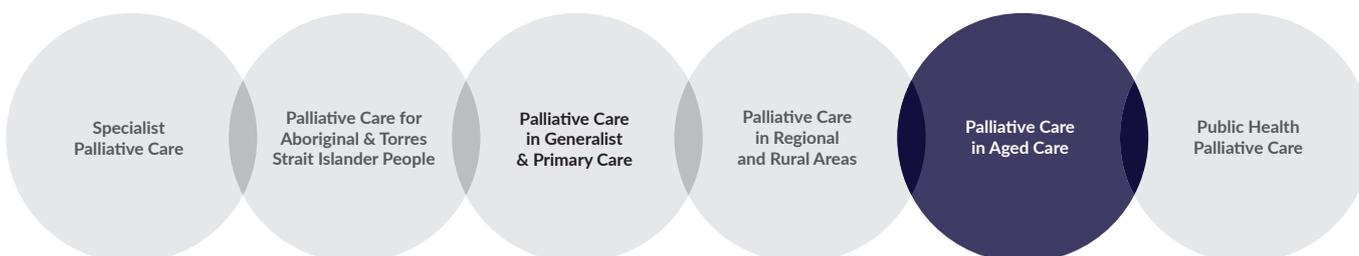


# 2020 Roundtable on Palliative Care in Aged Care

## A Summary of Key Improvement Areas

- Where they have capacity, GPs should be the centre of care planning and provision in aged care for palliative care. To support GPs: increase connections with specialist palliative care teams to provide advice and support, equip primary care providers with training, and remunerate them appropriately.
- Build capacity and capability for aged care workforce training and resources (including improved technology) that are specific to palliative care needs of people living in aged care settings (from diagnosis to bereavement).
- Embed a culture of quality palliative care in aged care. Develop strategies to respond to the high workforce turnover in aged care to ensure provision of consistent and high-quality palliative care.
- Support people to stay socially connected throughout the palliative care journey, recognising the important role of family, carers and community in aged care.
- Enhance psychosocial, spiritual and bereavement care to those receiving aged care support, their families and the workforce.

Key Improvement Areas identified at the Palliative Care in Queensland Summit 2020 Roundtables



# 2020 Roundtable on Public Health Palliative Care

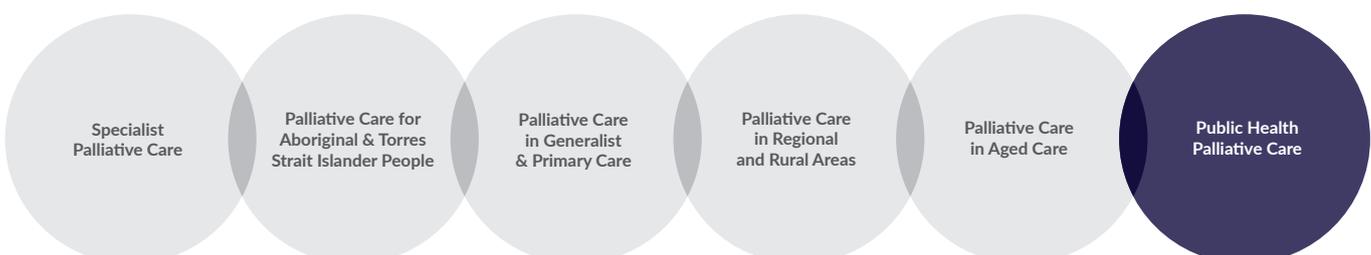
## A Summary of Key Improvement Areas

- When working with communities, identify and map local assets using a strength-based approach, showcasing the assets and providing navigation tools to improve local awareness and capacity. This is particularly useful in regional and rural areas and culturally and linguistically diverse groups, due to their existing social capital.
- Increase relationships, collaborations and partnerships (including Local Government Areas, committees, disability groups, consumers, neighborhood houses and systems) not only for awareness raising but to build on reciprocal relationships for planning, capacity building, evaluation and social impact.
- Conduct community awareness campaigns which support attitudinal shifts (less focus on only cure and fear of death, and more focus on improving quality of life through palliative care). Collect palliative care stories and showcase these. Everyone has a story and a connection in this space; the power of stories will effect change.
- Strengthen the role of community to participate in palliative care, recognising that palliative care is everyone's business. Develop roles within Compassionate Communities, promoting circles of care, connections, and navigation to increase death and compassion literacy, and increase collaboration with health, social and community supports.
- Develop templates and toolkits for individuals and collectives to empower themselves with best practice, information, tools, supports and networks. Develop a central repository which includes templates and toolkits.

## *Share with us when you utilise the 2021 Palliative Care in Queensland Priorities and/or the Roundtable Key Improvement Areas*

Let us know how you'll promote the Priorities - or any actions you've already taken!

Key Improvement Areas identified at the Palliative Care in Queensland Summit 2020 Roundtables







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