Response to the Royal Commission into Aged Care Quality and Safety
Consultation Paper 1 - Aged care program redesign: Services for the future

Submission to:
Palliative Care Australia

Submitted by:
Palliative Care Queensland

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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. Queensland Compassionate Communities (QCC) is the community arm of Palliative Care.

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

Our key priorities are that:

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

Contacts:

John Haberecht, President, PCQ State Council
president@palliativecareqld.org.au

Shyla Mills, CEO
shyla@palliativecareqld.org.au
Introduction

In December 2019, the Royal Commission into Aged Care Quality and Safety (hereafter referred to as “the Commission”) released its first consultation paper. This paper put forward a new model to approach aged care that hopes to make it easier for Australians to find and receive aged care services, whether at home or in a facility.

The consultation paper is entitled “Aged care program redesign: Services for the future” and was released to seek input on how to improve the design of the proposed model.

Palliative Care Australia (PCA) provided a submission to the Commission in October 2019, and was invited to provide further feedback on the model proposed in Consultation Paper 1.

PCA then asked its member organisations if they would like to collaborate on a response, inviting input on the key points made in the original PCA submission to the Commission.

The following pages detail the submission that Palliative Care Queensland (PCQ) made to PCA. The points focus specifically on palliative care as it relates to aged care.

How Palliative Care Queensland developed its reply

The recommendations in this report arise from an Annual Summit held in Brisbane on 2 December 2019, hosted by Palliative Care Queensland.

The one-day Summit brought together 104 delegates from multidisciplinary backgrounds including leaders, healthcare professionals, advisors, sector advocates and community members to debate and discuss the challenges facing palliative care.

A subset of the group came together in a Roundtable to discuss aged care. The priorities that this group determined form the basis for the following recommendations.


Part 1: Recommendations to improve Specialist and in reach services

The "Aged care program redesign: Services for the future" consultation report put forward the following question regarding Specialist and in reach services: How could the aged care and health systems work together to deliver care which better meets the complex health needs of older people, including dementia care, as well as palliative and end of life care? What are the best models for these forms of care?

As previously indicated, on 2 December 2019, the Palliative Care in Queensland Community came together to discuss priorities for the sector in 2020. A subset of the group met in a roundtable discussion which focused on aged care.

The group put forward the following priorities to improve palliative care in aged care:

**Priority 1:** Improve the continuity across the care continuum, particularly in relation to transitions from home-based care to acute care to Aged Care (Facility or Home care).

**Priority 2:** Increasing consumer and volunteer engagement.

- 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).

- Australians need help to clarify what palliative care is, and what it isn’t. For their sake, we need to begin to have these conversations on palliative care much earlier.

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

- 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.

- We need to consider innovative ways to begin these discussions early.

**Priority 4:** Ensure that aged care clients have access to both Specialist Palliative Care Services and generalist services.

- Use communication technologies to bridge the gap.

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

**Priority 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.

- 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 aged care context.
Part 2: Recommendations specific to the PCA Submission

The Aged Care Roundtable discussions put forward the following recommendations, organised into the Key Points made by PCA in their original submission to the Commission.

1. PCA Key Point: Whole of Government

   PCA Key Point:

   Whole of Government » Improve communication systems between services and sectors to minimise inappropriate transfers, support discharge planning and ensure necessary information is provided at the time of transfer. » Fully implement the National Palliative Care Strategy 2018 ensuring aged care is included. » Appoint a National Palliative Care Commissioner. » Make palliative care a COAG priority. » Ensure clearer funding and program responsibilities across State, Territory and Commonwealth jurisdictions.

   PCQ Reply:

   o Create a robust system that anticipates the future care needs of all Australians, especially with respect to demographic changes and increased rates of dementia and multi-morbidities.

2. PCA Key Point: Workforce

   PCA Key Point:

   Workforce » The Australian Government should fund the full implementation of the Aged Care Workforce Strategy. » Mandatory palliative care training for all those working in aged care including nursing, allied health, medical and care workers. » Appropriate remuneration for GPs attending residents in aged care facilities and conducting home visits which recognises the complexity of the clinical care required by some older people living with life-limiting illness.

   PCQ Reply:

   o Ensure all aged care services have (access to) a specialist palliative care service according to the Palliative Care Services Development Guidelines (PCA, 2018).

   o Establish a competency-based framework, with associated education and training, for generalist and specialist palliative care service providers who support those in aged care.

   o Set targets to increase aged care clinician access to on-line federally supported education programs, e.g. the CareSearch MOOC on death, dying and palliative care (5 weeks) as part of hospital-based continuing education programs.

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

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

   o As part of the Palliative Care Clinical Network, create a mechanism to share successful models that illustrate how to effectively and efficiently provide palliative care in aged care.
Explore the feasibility of a 24-hour support service for aged care providers to access generalist and specialist palliative care advice.

Increase access to Indigenous Health Workers and other supports for Aboriginal and Torres Strait Islander peoples diagnosed with a life limiting disease.

Use specialist (hospital-based) palliative services as hubs for generalist palliative care services, for integration into aged care and older adult services, including a focus on general medicine and rural and remote health services.

Integrate specialist palliative care services into settings beyond hospital including community and residential aged care to support Australians across the lifespan who prefer to die at home.

Improve transitions between facilities and services, e.g. exploring the role of transition coordinators/nurse navigators in generalist palliative care service delivery.

3. PCA Key Point: Community Awareness and Mobilisation

PCA Key Point:

Community awareness and mobilisation » Fund a sustained multifaceted community awareness campaign to normalise and support discussions of death, dying and palliative care. » Promote the benefits of advance care planning discussions. » Promote better understanding of the holistic nature of palliative care so people recognise the benefits of commencing palliative care early after diagnosis with a life-limiting illness.

PCQ Reply:

Promote public health palliative care.

Increase community awareness of death as a natural part of life by partnering with groups such as Compassionate Communities to deliver programs in aged care systems (such as death café, advance care planning, and bereavement seminars).

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

Offer a once-only awareness campaign about what they can expect from high quality palliative care services in aged care.

Improve access to community-based palliative care services that are available to those in aged care, e.g. with an annually updated list of community assets.

Raise community expectations regarding standards for quality palliative care in aged care.

Build on social capital to develop sustainable volunteer programs for palliative care in aged care (home-based and institutional) and the wider community (including those aged care clients living in rural and remote settings).
4. **PCA Key Point: Research, Data, and Advance in Technology**

**PCA Key Point:**

Research, data and advances in technology » Establish National Minimum Data Sets (NMDS) for palliative care which includes both health and aged care. » Introduce a Palliative Care ‘Field of Research’ with the addition of funding specific to palliative care within aged care research.

**PCQ Reply:**

**Data:**

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

**Research:**

- Target local and state-based research funding to align researcher interests with health service needs. For example, in the next three years target implementation research, investigating the best ways to implement established, evidence-based models of palliative care into aged care systems.
- Support targeted government funding for federal and state-based research to investigate the best ways to implement the National Palliative Care Strategy across diverse health and community settings.
- 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 State Industry grant programmes.

**Technology:**

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

5. **PCA Key Point: Best Practice and Innovative Models**

**PCA Key Point:**

Best practice and innovative models » Palliative care must be included and clearly articulated in the Aged Care Quality Standards. » Develop and fund innovative models of care to ensure older people have equitable access to palliative care and specialist palliative care.

**PCQ Reply: Refer to other sections**

6. **PCA Key Point: Funding Models**

**PCA Key Point:**

Funding models » The operation of the National Prioritisation System for Home Care Packages (HCP) be more transparent. » Require greater consistency in how priority for HCPs is assessed. » Simplify all communication with consumers about assessment, approval and assignment of their
HCP. » Additional funding be allocated to reduce the length of time people are waiting for an HCP at the level for which they have been assessed. » A palliative care supplement be made available for people in receipt of any level of HCP living with a life-limiting illness whose needs exceed the value of their package. » Undertake a micro study to ensure the new residential funding model (Australian National – Aged Care Classification AN-ACC) adequately addresses palliative care needs. » The MBS Review Taskforce consider how relevant MBS items can be better aligned with contemporary palliative care clinical evidence and practice, including the roles of general practitioners, nurse practitioners, allied health and community-based specialist palliative care providers. » The Australian Government should provide adequate funding to ensure timely access to high quality respite care.

PCQ Reply:

- To ensure that services are available to all Australians in metro, regional, rural and remote aged care service locations, federal models for specialist palliative care in reach services must be supported by direct, transparent and accountable funding that is flexible and fit for purpose.
- Target state funding to meet clear performance criteria and goals for the place of palliative care services within aged care (and general medicine and other in reach services).
- Align reimbursement for General Practitioners who offer generalist palliative care services to aged care patients with contemporary business models for medical services.
- Extend funding to support advance care planning in aged care.

7. PCA Key Point: Grief and Bereavement

PCA Key Point:

Grief and bereavement » Aged care providers should be supported, resourced and funded to provide grief and bereavement support, including for staff.

PCQ Reply:

- Develop bereavement services to increase reach across settings.
- Look to models that support the self-management of grief.
- Increase supports for rural and remote practitioners who work in aged care and support the bereaved, including telehealth and other technologies for support and supervision.

8. PCA Key Point: Access to Medicines

PCA Key Point:

Access to medicines » Anticipatory prescribing for people with palliative care needs should be accommodated by establishing imprest systems in residential aged care. » Education and ongoing support in handling, storing, administering and disposing of medicines safely to be available to carers and family of older people living at home with a life-limiting illness.

PCQ Reply:

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