

30 April 2018

Closing the Gap Refresh
Department of Prime Minister and Cabinet
[Online submission]

To whom it may concern

Input into Closing the Gap Refresh - The Next Phase: Public Discussion Paper

Thank you for the opportunity to provide input into your consultation process following the release of the Closing the Gap Refresh Discussion Paper. Palliative Care Australia (PCA) welcomes the opportunity to raise issues about the availability and access to culturally appropriate palliative care to Indigenous Australians.

PCA is the national peak body for palliative care in Australia, providing leadership on palliative care policy and community engagement. Working closely with consumers, its Member Organisations and the palliative care and broader health workforce, PCA aims to improve the quality of life and death for people with a life-limiting illness, their families and carers.

Palliative care is for people of any age who have a life-limiting illness that cannot be cured, where the primary treatment goal is to optimise the quality of life. Palliative care is person and family-centered care that offers a support system to help people to live their life as fully and as comfortably as possible until death, and to help families cope during this illness and in their bereavement. The values underpinning palliative care and end-of-life care are consistent with Aboriginal and Torres Strait Islander values of kinship, culture and community.

The Closing the Gap Refresh provides an opportunity to address the need for culturally appropriate models of care that enable timely access to palliative care and end-of-life care.

Specific issues that need to be explored include:

- Process to ensure it is not assumed that all Aboriginal and Torres Strait Islander peoples have the same cultural or religious requirements at the end-of-life and following death.
- The need to 'return to country' at the end of life.
- Community-based local approaches to palliative care, which leads to a significant role for Aboriginal and Torres Strait Islander health professionals in the delivery of quality end-of-life care.

- To understand that all Aboriginal and Torres Strait Islander communities in Australia have a common heritage of loss, and that for an individual close to death and for their family and community, the impact of the loss and grief is often compounded by earlier experiences.

Since our participation as a founding member of the Closing the Gap Committee in 2006, PCA has continued to be involved in a number of important projects aimed at improving health outcomes and creating opportunities for Aboriginal and Torres Strait Islander Peoples. PCA works closely with organisations representing the needs of Australia's Indigenous communities to strive to improve access to quality care at the end of life.

Recently, PCA hosted an Indigenous Roundtable on 22 February 2018, which brought together key stakeholders to discuss the challenges, issues and opportunities for Aboriginal and Torres Strait Islander people in the delivery of palliative care and end-of-life care service delivery to assist in informing PCA's workplan. PCA were appreciative of the time and commitment to this meeting by representatives from:

- Aboriginal Medical Services Alliance Northern Territory (AMSANT)
- Apunipima Cape York Health Council
- Australian Indigenous Doctors' Association (AIDA)
- Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM)
- Indigenous Allied Health Australia (IAHA)
- National Aboriginal and Torres Strait Islander Health Worker Association (NATSIHWA)
- Townsville Hospital, Queensland Health
- Australian Healthcare and Hospitals Association (AHHA)
- CareSearch, Flinders University
- Centre for Palliative Care Research and Education (CPCRE), Queensland University of Technology
- Program of Experience in the Palliative Approach (PEPA), Darwin

This submission is in part based on feedback from this Roundtable. PCA notes the current targets for Closing the Gap, which have focused on education and employment outcomes, improvements to life expectancy and to halve the gap in mortality rates for Indigenous children under the age of 5 year. These have been understandably high level targets that are essential to enable the same opportunities and life outcomes for Indigenous Australians as those for non-Indigenous Australians. However, I highlight to the Committee that palliative care forms an important component of the overall health continuum and there are particular aspects to consider for Indigenous Peoples.

Regarding how the Closing the Gap targets could better measure what is working and what is not, I draw your attention to the low rates of use of specialist palliative care services by Aboriginal and Torres Strait Islander people relative to their high rates of premature mortality. PCA believe there is plenty of scope for measures that will assess whether access to appropriate palliative care is working, or not working for Indigenous Australians. Data from the Palliative Care Outcomes Collaboration (PCOC)¹ from 2017 shows that only 1.4% of people accessing specialist palliative care services were of Aboriginal and/or Torres Strait Islander origin. In addition, the Australian Institute of Health and

¹ PCOC (2018) 'Patient Outcomes in Palliative Care in Australia: National report for July – December 2017'. Refer to www.pcoc.org.au

Welfare (AIHW) collects data on Indigenous Australians being admitted for palliative-care related hospitalisations. The latest data records an unsurprising over representation, with the rate of palliative care-related hospitalisations in public hospitals about twice as high for Indigenous Australians as for other Australians (41.5 and 20.5 per 10,000 population, respectively).²

Barriers to use of palliative care services include, but are not limited to, communication and cultural issues about the approach to dying, lack of knowledge and understanding about palliative care and the support this can provide within Indigenous communities, and the costs of transport and accommodation to access specialist palliative care services that are off country for people living in rural and remote communities. Further, grief and bereavement are often compounded by a lack of understanding and/or policies and procedures of health services that impact on the ability of people to follow tradition, such as large gatherings towards the end-of-life, smoking ceremonies, and the need to have family surrounding a person at all times, including after death.³ Following this are issues with returning a person to country after they have passed, which can be costly to a family and be hard to organise logistically.

PCA believe a key target or commitment that should be measured in a refreshed Closing the Gap agenda is more support for culturally appropriate palliative care and end-of-life care provision on country, which allows access to family and community support, in addition to models of care that support culturally appropriate grief and bereavement practices.

To note in our 2018-19 pre-Budget submission⁴, PCA has called for a number of measures to support palliative care for all Australians. Specifically in the area of national leadership, PCA want COAG to identify palliative care as a national health priority, and for the appointment of a National Palliative Care Commissioner. The focus of such a position would include establishing a partnership with state and territory governments to assess the needs of different regions and populations, in particular Aboriginal and Torres Strait Islanders and rural and remote populations.

Thank you for the opportunity to be part of this important work towards the next phase of Closing the Gap.

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² AIHW, *Palliative Care Services in Australia*, last update: 18/10/17,v6.0.

³ Wynne-Jones M, Hillin A, Byers D, Stanley D, Edwige V, Brideson T1 (2016) Aboriginal grief and loss: a review of the literature. *Australian Indigenous Health Bulletin* 16(3). Retrieved [27/4/2018]

⁴ http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/01/PCA024_Pre-Budget-Submission-2018-19.pdf