

Palliative care for under-served populations and people with complex needs

Summary of stakeholder workshops

Introduction

The Australian Government Department of Health has engaged Australian Healthcare Associates (AHA) to undertake an exploratory analysis of barriers to accessing quality palliative care for the following under-served population groups in Australia:

- Aboriginal and Torres Strait Islander people
- People from culturally and linguistically diverse (CALD) backgrounds
- Refugees
- People with a disability
- People experiencing homelessness
- People who are lesbian, gay, bisexual, transgender or intersex (LGBTI)
- Prisoners
- Veterans
- Care leavers (which includes Forgotten Australians, Former Child Migrants and Stolen Generations) and people affected by forced adoption or removal.

The objectives of the project are to:

- Identify unmet palliative care needs for each population group
- Consider cultural and personal factors influencing uptake of palliative care services
- Identify best practice approaches in palliative care settings
- Consider how trauma-informed approaches to care can foster a safer care environment and improve palliative care uptake and delivery
- Consider the role of advance care planning in addressing unmet needs
- Identify effective strategies for government and palliative care service providers to better engage with and provide services for people who identify as members of one or more of the identified groups.

Following a review of the literature, individual consultations with key stakeholders and a national online survey, workshops were held in each Australian capital city between September and November 2018 to further explore the issues affecting access to palliative care for the identified populations.

This document provides a summary of high-level insights gleaned from the workshops.

About the workshops

Aims

The overarching objectives of the half-day workshops were twofold: to share findings from the project to date, and to further explore the issues affecting access to palliative care for the identified populations. Specifically, the aims of the workshop were to explore:

- Successful approaches for supporting access to palliative care for the population groups
- The potential role of Advance Care Planning (ACP)
- Trauma-informed approaches to palliative care
- The roles of different stakeholder groups (including government, palliative care services and other service providers) in engaging with, and improving access for, the population groups
- Effective ways to engage relevant communities to capture end-user voices.

Prior to the workshop, participants were sent a jurisdiction-specific discussion paper, which provided background information relevant to workshop discussion topics. AHA facilitators delivered the workshops, which involved short presentations and small group discussions. Where possible, participants were asked to separate into groups relating to each of the identified under-served populations, although the degree of intersectionality both within the population groups being considered and the interests of workshop attendees is acknowledged.

Participants

Workshop participants comprised service providers (including specialist palliative care services, other health services and support services that work with the population groups), peak body representatives, academics and government representatives. Overall, the workshops were very well attended, with 170 people participating across all major cities as shown in the table below, and two online focus groups held for those unable to attend in person.

Workshop location	Date	Attendance (n)
Brisbane	9 September	29
Hobart	11 September	13
Canberra	4 October	26
Sydney	5 October	17
Adelaide	9 October	25
Perth	10 October	17
Darwin	19 October	15
Melbourne	1 November	28
Online focus groups	8 & 12 November	5
Total		175

Key themes

Discussion session 1: Barriers and promising approaches

Participants were asked to reflect on the findings presented in the discussion paper. In particular, they were asked to identify key messages and stand-out approaches to addressing barriers to accessing palliative care.

Participants reported few surprises concerning the barriers to accessing palliative care for each population group. Common themes elaborated upon included:

- A lack of understanding of palliative care (across the population in general, and among under-served populations in particular)
- Heterogeneity within the identified population groups, as well as cross-over (i.e. individuals belonging to a number of these groups)
- The importance of person-centred care (but a potential lack of resourcing and/or accountability for providing it)
- The need for early referral to palliative care, as well as holistic care and information sharing to facilitate seamless transitions through the system.

Discussion session 2: Trauma-informed approaches to palliative care

Participants were invited to consider the extent to which trauma-informed approaches are being utilised in palliative care delivery for under-served populations, and how this approach may improve palliative care uptake and delivery.

Familiarity with, and understanding of the term 'trauma-informed care' varied widely. It was reported that social workers and psychologists, as well as those working with homeless populations, care leavers, and those affected by forced adoption may be more familiar with trauma-informed approaches than others.

For some stakeholders, trauma-informed care was considered synonymous with person-centred care, and part of palliative care services' core business. Other stakeholders felt that it may be out of scope for – or actively avoided by – many health professionals in the palliative care setting.

In particular, there was confusion and concern over whether the desired outcome of trauma informed approaches was treatment of trauma specifically, or understanding it (and triggers) in order to provide comfort at end-of-life. Generally, approaches aimed at psychological recovery were felt to be needed much earlier than could be provided in a palliative care context, while psychological safety and comfort were considered to be paramount.

Some felt that trauma-informed approaches should form a core part of training and education for all health providers. Others felt it was more applicable for those working specifically with these population groups (rather than in health or palliative care), noting that it sits more comfortably in a psychosocial, rather than medical, model of care.

Discussion session 3: Advance care planning

Participants were asked to discuss the role of advance care planning (ACP) in improving access to person-centred palliative care.

In theory, ACP was considered useful for all under-served populations, in terms of opening conversations between individuals, families and health care providers around preferences for end-of-life care. However, significant issues were also identified, including:

- Potential characteristics or circumstances of some of the identified population groups which may impact the effectiveness of ACP (i.e. transient housing, social isolation, disenfranchisement, fear of government/authority)
- Logistical issues of completing official documents (including onerous processes and difficult documentation) and appropriate storage to ensure access for health professionals at the relevant time/place
- Even when done, many reported anecdotally that an individual's documented plan may not be adhered to (e.g. families may over-ride individual wishes).

Stakeholders also noted a perception among health professionals that it's nobody's specific role to support consumers in ACP. It was reported that while it should ideally occur early (and before an individual arrives in a palliative care setting), and GPs may be well-placed to facilitate the process, many were considered to be uncomfortable engaging in these conversations, or not see it as their role.

Opportunities to improve ACP included community education, practical support to complete ACPs, and the use of community champions to promote the concept.

Discussion session 4: Priority recommendations

Participants were asked to brainstorm recommendations for improving access to palliative care for under-served populations at a number of levels. Common recommendations for various stakeholder groups related to the following:

For governments

- Long-term, stable funding, including for:
 - Staffing
 - Information resources
 - Models of quality palliative care (including multiple avenues of access, referral pathways and community-based services)
 - Education and training
 - Service provision across all areas (including rural and remote)
 - Research/data collection
 - Raising community awareness
 - A support service to navigate the system
 - Advocacy regarding ACP.

- Address gaps between palliative care sector, aged care sector and National Disability Insurance Scheme (NDIS).

For health service providers

- Improve the sector's understanding of palliative care, including when to refer (i.e. early)
- Provide individualised, wrap-around packages of care (including care coordination and case management)
- Education and training to upskill the workforce (e.g. in culturally-sensitive care, trauma-informed approaches, issues affecting and needs of under-served populations)
- Provide better access to interpreters (for CALD groups, refugees, Aboriginal and Torres Strait Islander people where required)
- Provide flexible models of care (e.g. outreach services)
- Ensure relevant links (e.g. for client engagement and service delivery) and comprehensive referral pathways for a seamless, holistic approach
 - Including access to psychosocial/psychological support
- Use telehealth to increase access (although not appropriate for all populations)
- Adopt a trauma-informed approach
- Engage with communities/community leaders.

For other stakeholders working with the identified population groups

- Community education/awareness raising activities (support for dying, death and grief)
- Engage community leaders/champions
- Connect, work, collaborate, partner and communicate effectively with other stakeholders and services (create networks)
 - Provide education to palliative care service providers
 - Adopt a 'Compassionate Communities' approach
- Engage with communities to hear their 'voice'
- Use peak bodies to promote understanding of palliative care.

For aged care providers

- Understand what services are available, improve access to information
- Adopt a culturally-appropriate approach
- Facilitate discussions around values and end-of-life care, including early engagement and planning with families (including ACP)
- Adopt a trauma-informed approach; understand potential impacts of trauma on behaviour
- Educate staff to improve empathy and understanding of population groups' needs, and improve communication skills
- Identify palliative care needs early
- Work with key service providers for the population groups.

For the broader community

- Promote awareness (regarding death and dying, palliative care, ACP, as well as challenges faced by under-served populations)
- Improve health literacy
- Use inclusive mainstream messages
- Develop/support community champions/advocates
- Address bias and stigma
 - Promote understanding, respect and compassion
- Explore community-based care options
- Support programs for 'Compassionate Communities', promote open conversations about life and death, normalise these topics/conversations.

Next steps: Community consultations

Many workshop participants across Australia have indicated support for assisting AHA in reaching members of each population group to capture community members' voices with respect to palliative care. These community consultations will be undertaken over the coming months through focus groups and interviews (via telephone or face-to-face).

Workshop evaluation results

Across all workshops (excluding online focus groups), 136 participants completed an evaluation form. The majority of participants provided positive feedback regarding their overall impressions of the workshop. Of 132 participants who responded to this question, 95% reported their overall impression was excellent or good (*Figure 1*).

Figure 1: Participants' overall impressions of workshops

