Australian Government Department of Health

Exploratory Analysis of Barriers to Palliative Care

Summary Policy Paper

September 2019

AHA **Australian Healthcare Associates**
Australia's largest health & human services consulting firm

Acknowledgments

Australian Healthcare Associates (AHA) would like to thank the many people who contributed to this project. These included palliative care and other health and social care providers, academics, and peak organisation and government representatives. In particular, we thank the people from the under-served populations who shared their thoughts and experiences with us.

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Executive summary

Australian Healthcare Associates was engaged by the Australian Government Department of Health in February 2018 to conduct an exploratory analysis of barriers to accessing quality palliative care for people from under-served populations or people with complex needs (the project).

Nine specific populations of interest were identified for the purpose of the project:

- Aboriginal and Torres Strait Islander peoples
- Care leavers and people affected by forced adoption

- People from culturally and linguistically diverse (CALD) backgrounds
- People with disabilities
- People experiencing homelessness
- People who are incarcerated
- People who identify as lesbian, gay, bisexual, transgender or intersex (LGBTI)
- Refugees
- Veterans.

The project was informed by a number of activities, as summarised below.

Project activities

Literature review	Key informant consultations	Stakeholder survey	Workshops	Community consultations
> 390 sources	> 100 interviews	414 responses	170 attendees	184 participants

Analysis and reporting

Summary Policy Paper
9 Issues Reports
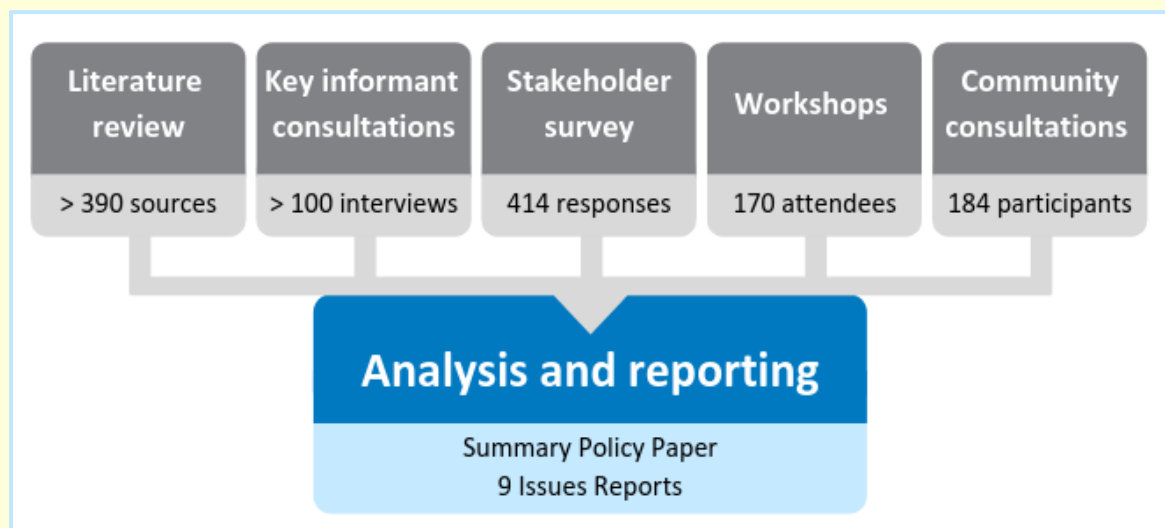
Introduction

Palliative care plays a vital role at the end-of-life for many Australians, reducing the physical and emotional distress of dying, and optimising quality of life for individuals, carers, family and friends.

Governments and service providers have increasingly focused on improving the availability of palliative care for all Australians with a life-limiting illness. Despite this, significant barriers remain—both for the Australian population as a whole and, more particularly, for a number of vulnerable, under-served population groups (listed above).

While there is significant diversity within and crossover between the nine populations of interest (and other vulnerable groups), there are also commonalities—in particular, barriers to accessing health care and community services in general. In the context of life-limiting illness, these populations may be described as 'doubly vulnerable'—i.e. 'both in need of palliative care services and experiencing deficits in the social determinants of health that result in complex, intersecting health and social concerns'.

Key findings and recommendations

The project identified a number of barriers to palliative care common across under-served populations, as well as universal barriers common to all Australians (see p.3). These universal barriers are likely to be magnified for members of the identified population groups.

The project also identified enablers and promising approaches to improving access to and delivery of quality palliative care for under-served populations. These, along with more detailed recommendations presented in *Chapter 4*, relate to seven domains that facilitate quality palliative care, underpinned by four key enablers (see p.32).

Findings and recommendations specific to each under-served population group are presented in separate issues reports.

Universal and common barriers to quality palliative care for people from under-served populations

CONSUMER-SIDE	SERVICE-SIDE
Lack of comfort discussing death and dying	Lack of relevant cultural awareness/competency within available services
Lack of understanding/awareness of palliative care	Lack of health worker skills/experience (in palliative care and/or working with people from under-served population groups)
Fear and mistrust (e.g. of Western medicine, health care services, perceived authority)	
History of trauma	Lack of available services and support to facilitate dying in setting of choice
Social/family breakdown, isolation	
Delayed diagnosis/presentation to healthcare services	Referral issues (lack of/late referral to specialist services)
Language and communication barriers	
Mismatching cultural understandings and preferences	
Fear/perception of stigma/discrimination/racism	Actual stigma/discrimination/racism
Financial constraints	Insufficient funding/ funding model issues

Facilitators and underpinning enablers of quality palliative care

Facilitators of quality palliative care

Timely initiation of palliative care

Community comfort with discussing death and dying

Appropriate communication and information provision

Provision of person-centred care

Community awareness and understanding of palliative care

Advance care planning

Greater understanding of under-served populations

Underpinning enablers

Networks, partnerships and collaborations

Workforce development

Financial support and resourcing

Research, evaluation and monitoring

1 | Background

Palliative care plays a vital role at the end-of-life for many Australians, reducing the physical and emotional distress of dying, and optimising quality of life for individuals, carers, family and friends.

Governments and service providers have increasingly focused on improving the availability of palliative care for all Australians with a life-limiting illness. Despite this, significant barriers remain— both for the Australian population as a whole and, more particularly, for a number of vulnerable, under-served population groups.

Australian Healthcare Associates (AHA) was engaged by the Australian Government Department of Health (the Department) in February 2018 to conduct an exploratory analysis of barriers to accessing quality palliative care for people from under-served populations or people with complex needs (the project).

Nine specific populations of interest were identified for the purpose of the project:

- Aboriginal and Torres Strait Islander peoples
- Care leavers and people affected by forced adoption
- People from culturally and linguistically diverse (CALD) backgrounds

- People with disabilities
- People experiencing homelessness
- People who are incarcerated
- People who identify as lesbian, gay, bisexual, transgender or intersex (LGBTI)
- Refugees
- Veterans.

The objectives of the project were 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 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.

About the population groups

The term 'under-served' has been deliberately chosen in the project to represent those population groups likely to have co-existing vulnerabilities and/or complex needs in relation to palliative care. It is intended to convey that the healthcare system is failing to provide equitable access and care for these groups, rather than implying such population groups are 'under-accessing' existing services.

The nine under-served populations identified within this project are diverse—indeed, each one is characterised by significant diversity. There is also significant crossover between the groups, with many individuals belonging to multiple population groups.

However, commonalities also exist. Many individuals within these groups share difficulties achieving the fundamental pre-requisites for health (as outlined in the Ottawa Charter for Health Promotion): peace, shelter, education, food, income, a stable ecosystem, sustainable resources, social justice and equity.[1] They also experience inequities in access to healthcare and community services in general, a higher likelihood of complex needs, and an increased incidence of exposure to psychological trauma.

All of these factors are of particular relevance in promoting access to and provision of quality palliative care for individuals within these population groups. However, palliative care services may not be responsive to the needs of those who may be described as 'doubly vulnerable'—i.e.

'both in need of palliative care services and experiencing deficits in the social determinants of health that result in complex, intersecting health and social concerns'.[2]

While the groups identified in this project largely align with those highlighted in Australia's *National Palliative Care Strategy 2018* (the Strategy)[3] and National Palliative Care Standards (the Standards),[4] not all under-served populations have been captured in this project. These documents list some groups that are not included in this project (people living in rural and remote areas, those who are ageing and frail, children, people living with mental illness and people living in residential aged care), and this project includes some groups not listed (veterans, care leavers and people affected by forced adoption, refugees).

Palliative care services may not be responsive to the needs of those who may be described as 'doubly vulnerable'.

Through the project, children and youth were identified by stakeholders as additional under-served population groups in the context of palliative care.

Methodology

The project ran from February 2018 to June 2019, and the main activities that contributed to the project are summarised in *Figure 1-1*.

The project generated high levels of engagement from a broad range of stakeholders from across Australia. More detail on the project methodology, including limitations, is provided in *Appendix B*.

Figure 1-1: Project activities
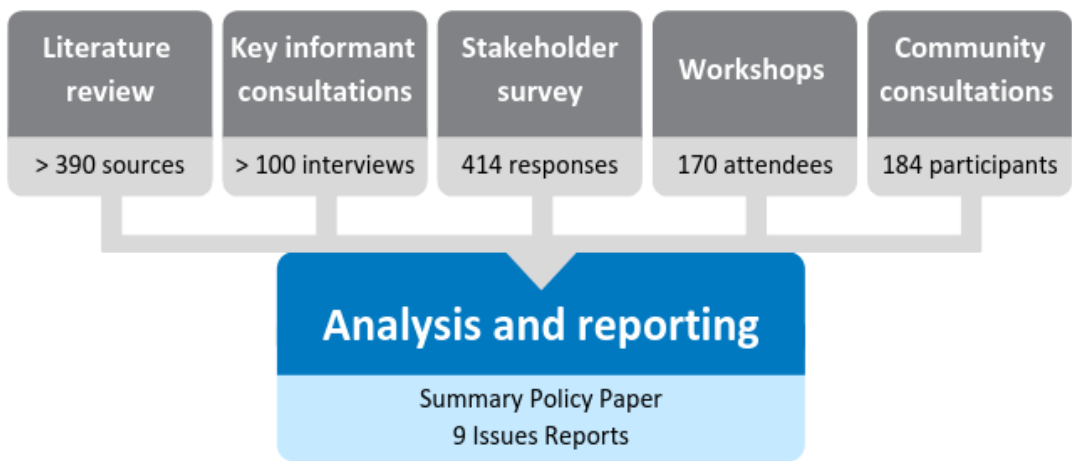
This policy paper

This *Summary Policy Paper* is part of a suite of documents developed through the project, as shown in *Figure 1-2*. Key resources developed from the project include a literature review and nine separate issues reports highlighting specific barriers and promising approaches to the delivery of palliative care for each identified population group. This document summarises some of the overarching themes relevant to the provision of palliative care to all under-served and vulnerable population groups, including key concepts pertaining to contemporary palliative care practice.

It also provides recommendations for the palliative care and other relevant sectors to improve access and quality of care for all Australians, but more particularly those currently experiencing inequities in accessing appropriate, high-quality palliative care services.

Brief summaries of key messages from the issues reports are provided in *Appendix A*.

Figure 1-2: Suite of reports

Summary Policy Paper

Issues Reports

- Aboriginal & Torres Strait Islander peoples
- Care leavers and people affected by forced adoption
- People from culturally and linguistically diverse backgrounds
- People with disabilities
- People experiencing homelessness
- People who are incarcerated
- People who identify as LGBTI
- Refugees
- Veterans

Literature Review

2 | Palliative care in Australia

This chapter provides a brief overview of the background and policy context for the delivery of palliative care in Australia, including key concepts, relevant approaches, the national policy context, jurisdictional roles and responsibilities and advance care planning.

Key concepts

A range of definitions exist for palliative care. The definition adopted for this project is provided on p.10.

Increasing demand for palliative care

There is growing recognition of the benefits of palliative care, and it has been recognised by the World Health Assembly as a human right.[5] However, there remains a gap between the vision of high-quality palliative care for all, and the reality that many people cannot access appropriate end-of-life care.

It is estimated that 50 to 90 per cent of the 160,000 people who die in Australia each year would benefit from palliative care, but many do not receive care that reflects their choices or meets their needs.[6] Those from the under-served populations considered in this project, as well as others, may face additional challenges in accessing high-quality palliative care.

Further, demand for palliative care is increasing over time—due to the growing (and ageing) population, along with growing rates of multi-morbidity, chronic progressive illnesses and diseases with high symptom burden.[7]

Dying in place of choice

Over time, care of the dying has become increasingly medicalised and institutionalised. Some have argued that this has occurred at the expense of social, psychological and spiritual aspects of care.[8] An estimated 60 to 70 per cent of Australians would prefer to die at home, yet only 14 per cent do so—with the vast majority dying in hospital or residential aged care.[8]

In Australia, recent palliative care policy places an emphasis on person-centred care (see p.15) and consumer choice, which brings a need for greater flexibility around all aspects of palliative care service delivery. This includes building the capacity of the system to support end-of-life care in the community, and an extension of the palliative care 'workforce' to include not just specialist palliative care teams and other health and social care providers, but a range of other service providers and community members (see *A public health approach* on p.11).

What is palliative care?

Palliative care is a person- and family-centred approach to care. Palliative care services are provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise quality of life.[9] It improves quality of life for individuals and families through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other physical, psychosocial or spiritual problems.[3]

Palliative care:

- Should be strongly responsive to the needs, preferences and values of people, their families and carers

- Should be available to all people with an active, progressive, advanced disease, regardless of diagnosis

- Affirms life while recognising that dying is an inevitable part of life.

This means that palliative care is provided during the time that the person is living with a life-limiting illness, but it is not directed at either bringing forward or delaying death.

Palliative care can be provided in a range of settings, including:

- At home

- At a hospital

- In a hospice

- In an aged care facility

- In an institutional setting (such as a correctional facility or accommodation for people living with a disability).

Palliative care involves a range of clinical and other supports delivered by different providers,

including volunteers, depending on the patient's needs. These may include:

- General practice and primary care

- Other specialist medical, nursing and allied health practitioners

- Community, disability, aged and social services

- Grief and bereavement services

- Specialist palliative care services (comprising multidisciplinary teams with specialised skills, competencies, experience and training in palliative care), for patients with complex needs.

This project adopts a broad view of palliative care, as outlined above, and is not limited to the provision of specialist palliative care services.

Therefore the term 'palliative care provider' is used in this document to refer to all health and social care providers involved in the delivery of palliative care.

Where relevant, the term 'specialist palliative care provider' is used to differentiate this group of professionals. More broadly, the term 'health and social care providers' is used to represent those within this category for whom palliative care is not considered core business.
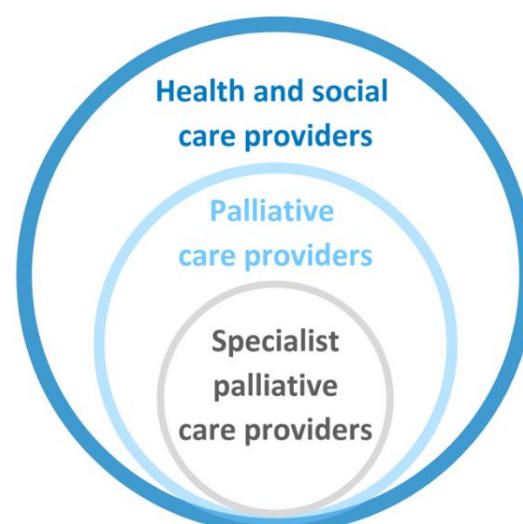
Relevant approaches

A number of key approaches, described in both the literature and in stakeholder consultations, are relevant to the provision of palliative care in general, and to the accessibility and appropriateness of care to under-served populations in particular. Three key approaches (public health, trauma-informed, and person-centred) are summarised below.

A public health approach

A public health approach to palliative care (sometimes referred to as 'health promoting palliative care') is a relatively new concept that moves away from a focus on clinical issues (such as control of symptoms), to a broader view of palliative care through the lens of community development, social research, bioethics and health economics.[10] A public health approach addresses the 'organisational, structural and cultural considerations required for systemic and sustainable change in end-of-life practice'.[11]

Public health approaches consider multi-faceted actions, aligned to the *Ottawa Charter for Health Promotion*:[1]

- Building healthy public policy
- Creating supportive environments
- Strengthening community actions
- Developing personal skills
- Re-orientating health services.

As noted in the *World Health Organization (WHO) Public Health Strategy for Palliative Care*, 'the process…is striving to integrate palliative care into all levels of the society—from the community level upward and from the palliative care expert…downward'.[12]

Because public health approaches strive to reduce health inequalities, they have particular relevance to under-served population groups.

'Caring for people who are approaching and reaching the end-of-life is everybody's business—everybody in health, aged and community care has a role to play' —National Palliative Care Standards

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By considering 'upstream' obstacles arising from policy, funding and resource constraints, as well as 'downstream' issues relating to staff members' knowledge, confidence and skills, public health approaches provide a useful framework for promoting high-quality palliative care in specific settings, such as primary care, residential aged care, and disability community living services.

'People living with a life-limiting illness will need to have palliative care provided in many different settings—in their homes, acute hospitals, hospices...general practices, specialist clinics, aged care facilities, and other organisations in which people may be living (such as correctional facilities and locations caring for people living with severe mental illness or severe disabilities)' —Palliative Care Service Development Guidelines

Compassionate Communities models are a subset of public health palliative care approaches that emphasise whole-of-community engagement around end-of-life care. A Compassionate Communities framework underpins the *Tasmanian Palliative Care Policy Framework 2017– 2021*,[13] as well as more localised projects such as many of those funded by the Australian Government through the *Greater Choice for At Home Palliative Care* measure.[14]

Trauma-informed approaches

Individual trauma 'results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional or spiritual wellbeing'.[15]

Exposure to psychological trauma is common in the general population, and prevalence in the palliative care context is even higher due to the effects of old age and/or serious illness.[16] While an estimated 14% to 24% of individuals exposed to trauma will meet the diagnostic criteria for post-traumatic stress disorder (PTSD), a much larger proportion will develop 'subclinical' or 'partial' PTSD, which is still associated with negative long-term effects.[16]

The diagnosis of a life-limiting illness is in itself a 'criterion stressor' in the diagnosis of PTSD,[17] and there is a higher incidence of PTSD in people with cancer and other life-threatening conditions than in the general population.[18,19] In addition to this, the need for palliative care often coexists with the psychological trauma imparted by 'months or years of escalating illness, health emergencies, intensive care unit stays, major medical interventions, and their increasingly intolerable side effects'.[16] These circumstances, along with loss of physical or cognitive function or transfer to an institutional setting, can cause or exacerbate existing trauma.[20]

Beyond these issues universally relevant to palliative care, there is an increased likelihood of experience of trauma within all nine of the under-served populations considered in this project. Although much of the available research on the effects of trauma at end-of-life focuses on veteran

populations,[16] the trauma experienced by other population groups may be directly related to sustained discrimination and/or abuse.[21] For others, experiences of trauma may have contributed to life circumstances such as homelessness or incarceration.

Trauma exposure can result in significant effects on individual health and wellbeing all the way through to the end-of-life.[16] Potential effects include depression, anxiety, PTSD, alcohol and substance misuse, and impacts on family, social and work life,[22] and these constitute a significant burden for individuals, families and communities.[15] Psychological trauma is linked with chronic physical, mental and behavioural health disorders,[15] and exposure to trauma can affect a person's experience of pain, particularly when coinciding with confusion, delirium or dementia.[16]

Those with a history of trauma may find trauma-related symptoms are triggered or exacerbated in the palliative care setting.[17] PTSD may manifest as difficulties with emotion processing and regulation, irritability, anger, jumpiness, flashbacks, nightmares, and anger.[16,19] For some, being touched in the context of medical care may be re-traumatising.[23]

PTSD can complicate the process of dying in a number of ways:

- The diagnosis of a life-limiting illness may mimic the original trauma, triggering distress

- The normal process of 'life review' can be tainted by traumatic memories, causing anxiety, sadness, guilt or anger

- A tendency to cope by avoiding or ignoring problems can lead to poor communication with health and social care providers and poor adherence to treatment

- Distrust of authority can lead to refusal of care

- Individuals may lack adequate caregiver support due to social isolation and avoidance.[18]

Many of these issues are relevant regardless of the origin of trauma-related symptoms and whether or not PTSD has been formally diagnosed.[19]

Trauma-informed care 'is an organisational structure and treatment framework that involves understanding, recognising and responding to the effects of all types of trauma'.

Trauma-informed care 'is an organisational structure and treatment framework that involves understanding, recognising and responding to the effects of all types of trauma'.[21] Such an approach requires knowledge of the prevalence of trauma in both the general population and specific population groups, and an organisation's response might include the integration of this information into policies and practices to prevent re-traumatisation of clients and promote organisational 'safety' for those affected.[16]

Trauma-informed approaches may be employed in interactions with all clients, but be of particular benefit to those affected by trauma.

Universal trauma-informed approaches do not necessarily require knowledge of an individual's history of trauma or treatment of trauma-related symptoms. Instead, trauma-informed approaches may be employed in interactions with all clients, but be of particular benefit to those affected by trauma.[23]

Such approaches can improve quality of care by alerting care providers to factors that may explain challenging behaviours, and issues with communication and regulation of emotion, thereby avoiding dismissal or stigmatisation of people as 'problem patients'.[20,24] They may also help to reduce patients' anxiety, build patient–provider rapport, and create safe and empowering services.[15,23]

The role of routine screening for trauma in healthcare practice is less clear, and may depend on providers' level of contact with patients and whether resources are available to respond to positive screening results. Even where time is not likely to be available to treat PTSD, interventions can focus on avoiding trauma triggers and subsequent re-traumatisation.[16]

Guiding principles for a trauma-informed approach

Important elements of a trauma-informed approach to care include:

- A focus on building therapeutic relationships that are empowering and support individual strengths

- Close collaboration with external agencies and expert consultants who can provide specialised advice and trauma care

- Careful consideration of the potential for re-traumatisation through inappropriate work practices and/or any continuing trauma in a person's personal life

- Embedding trauma-informed care approaches in policies and workplace practices across the service

- Educating and training staff regarding the prevalence and impacts of trauma

- An assumption that everyone accessing the service has potentially experienced trauma, and recognition of the need to adopt trauma-informed approaches in all aspects of the service's treatment and care.[25]

Person-centred care

The concept of person-centred care is becoming embedded in many areas of health care. Person-centred care is 'respectful of, and responsive to, the preferences, needs and values of patients and consumers. The widely accepted dimensions of person-centred care are respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers, and access to care'.[26]

For under-served population groups, key components of person-centred care may include **culturally-appropriate care** (especially for Aboriginal and Torres Strait Islander peoples, people from CALD backgrounds and refugees) and/or **trauma-informed approaches** (see p.12).

'Family means different things to different people'
—Stakeholder workshop participant

In the context of palliative care in particular, the notion of '**family-centred care**' is important, as palliative care is designed to support a person's family as well as the individual through the progression of a life-limiting illness and death. However, the meaning of 'family' is individual, and may be more likely among under-served populations to include 'non-traditional' members. Family may include people who are biologically related and people who joined the family through marriage or other relationships, as well as 'family of choice' and friends.[9] More simply, it might be conceptualised as those

people a patient would choose to invite when the clinician asks for a 'family meeting'.[27]

However, the concept of person-centred care may be challenging in practice, especially where individual decision-making is at odds with cultural values, or where individuals are reluctant or unable to express their preferences or make choices about their care. Some people from under-served population groups may have little experience of being asked about their preferences or having choice ('having a voice'), and person-centred care may require health and social care providers 'to know what it is like to live "a certain kind of life"'.[28]

For these reasons, best-practice health care—particularly for those from under-served population groups—may be better articulated as '**relationship-centred care**', highlighting the importance of relationships between individuals, families, health and social care providers from all disciplines, other support service providers and the wider community.[28]

> *'Palliative care needs to be relationship-based care. The importance of the relationships is magnified, and marginalised populations have an even greater need for relationships and support to help them feel in control and feel trust and stability'*
> *—Stakeholder workshop participant*

For the purpose of this policy paper, the term 'person-centred care' is used to encompass the concepts of family- and relationship-centred care, as relevant to individuals and families throughout their palliative care journey.

National policy context

National policies and frameworks guide palliative care service provision in Australia. *The National Palliative Care Strategy 2018* provides an overarching vision that 'people affected by life-limiting illness get the care they need to live well'.[3] A guiding principle of the Strategy is that 'all Australians will be able to access quality palliative care' (p.11), recognising that a number of populations are under-served.

The Strategy intersects with a range of other national policies. Those of particular relevance to this project include:

• National Carer Strategy

• National Framework for Action on Dementia (2015-2019)

• National Disability Strategy 2010-2020

• National Aboriginal and Torres Strait Islander Health Plan (2013-2023).

Palliative Care Australia (PCA) is the national peak body for the palliative care sector, and is funded by the Australian Government. PCA is responsible for developing the national standards for palliative care and other guidance documents to support the Strategy. The 5th edition of the *National Palliative Care Standards* (the Standards) was released in 2018. While intended for specialist palliative care services, the Standards (see box) provide a useful overview of the 'ideal' palliative care experience.

Standard 1—Initial and ongoing assessment incorporates the person's physical, psychological, cultural, social and spiritual experiences and needs.

Standard 2—The person, their family and carers work in partnership with the team to communicate, plan, set goals of care and support informed decisions about the care plan.

Standard 3—The person's family and carers needs are assessed and directly inform provision of appropriate support and guidance about their role.

Standard 4—The provision of care is based on the assessed needs of the person, informed by evidence and is consistent with the values, goals and preferences of the person as documented in their care plan.

Standard 5—Care is integrated across the person's experience to ensure seamless transitions within and between services.

Standard 6—Families and carers have access to bereavement support services and are provided with information about loss and grief.

Standard 7—The service has a philosophy, values, culture, structure and environment that supports the delivery of person-centred palliative care and end-of-life care.

Standard 8—Services are engaged in quality improvement and research to improve service provision and development.

Standard 9—Staff and volunteers are appropriately qualified, are engaged in continuing professional development and are supported in their roles.

The Standards are mapped against other key, national quality standards and statements such as:

- The Australian Commission on Safety and Quality in Health Care (ACSQHC) *National Safety and Quality Health Service Standards* (Version 2)

- The ACSQHC *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care* (2015)

- The ACSQHC *National Consensus Statement: Essential Elements for Safe and High-Quality Paediatric End-of-Life Care* (2016)

- The Accreditation Standards, as identified in the *Quality of Care Principles 2014* and administered by the Australian Aged Care Quality Agency.

PCA also produced updated *Palliative Care Service Development Guidelines* in 2018. These updated guidelines are intended to communicate the expectations of PCA for:

- The range of palliative care services that should be available to people living with a life-limiting illness, their families and carers

- The workforce and system capabilities required to deliver an effective network of palliative care services using a population-based and geographic approach to service planning.

In addition to providing overarching policy direction and guidance, the Australian Government funds PCA and Advance Care Planning Australia (ACPA) as well as a number of national palliative care projects and initiatives focused on education, training, quality improvement and advance care planning.[29]

Jurisdictional roles and responsibilities

While the Australian Government provides overarching policy direction and funding support for palliative care to the states and territories, delivery of care is largely determined at state/territory level, informed by priorities set out in local strategies or palliative care service plans. State/territory policy documents specify different priority populations, which vary between jurisdictions, and do not always include all groups identified in the Strategy. As a result, there are some jurisdictional variations in service delivery models, including the focus placed on different population groups.

Advance care planning

The process of advance care planning involves conversations about future healthcare preferences between a competent person, healthcare providers and potential substitute decision-makers. The outcomes of the process can include the development of statutory or non-statutory advance care directives (ACDs), or other, less formal documentation of a person's preferences and substitute decision-maker.[30]

Advance care planning is 'a process of planning for future health and personal care whereby a person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their

decisions'.[31] While not solely related to palliative care (see *Figure 2-1*), the existence and implementation of an advance care plan can significantly improve the quality of end-of-life care.[8]

The Australian Government provides funding to ACPA to support Australians in decision-making about their life and healthcare. ACPA delivers projects with partners across health sectors and non-government organisations and works to build workforce capability and improve knowledge and awareness of advance care planning in the community.

While legislation and processes regarding advance care planning vary between jurisdictions, ACPA aims to 'build the foundation for a national collaborative approach to advance care planning'.[32]
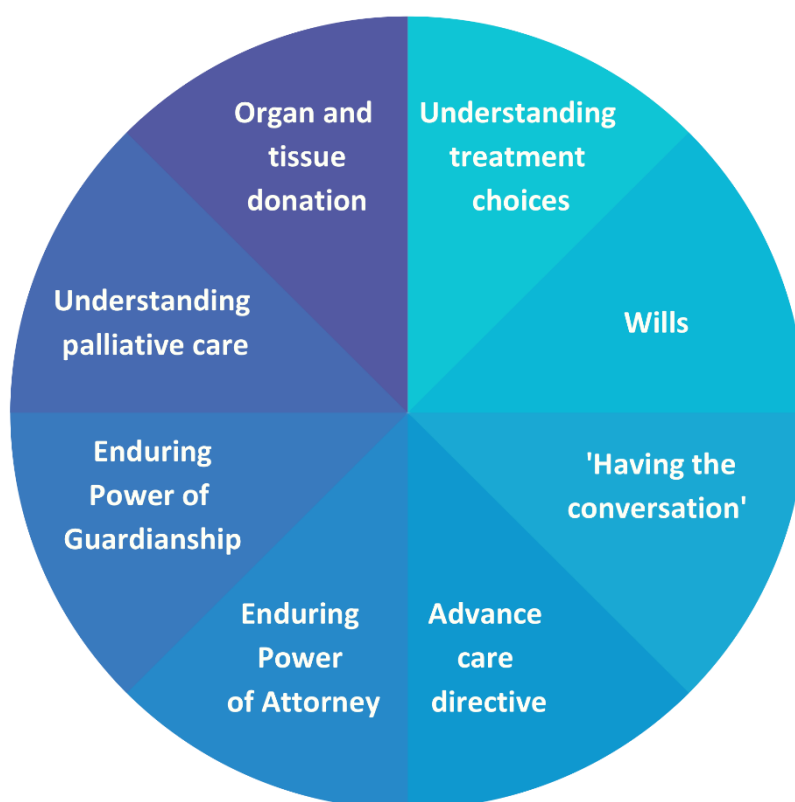

Figure 2-1: Elements of advance care planning

Source: Palliative Care Western Australia[33]

3| Project findings

Specific contextual factors relating to palliative care access for people from each under-served population group are highlighted in the relevant issues report (see *Figure 1-2*).

However, AHA acknowledges that these population groups are not homogeneous: there is great diversity within these populations as well as significant crossover between them, with many individuals belonging to more than one of these groups, and having other life circumstances and experiences that will shape their needs and preferences from time of diagnosis with a life-limiting illness to end-of-life care and death.

In addition, AHA acknowledges that the community members consulted for this project may not be representative of their broader communities. In particular, it is likely that those who participated had a greater understanding of palliative care, and felt more comfortable discussing death and dying, than those who didn't participate and may be more 'difficult to reach'. Refer to *Appendix B* for more information on project methodology and limitations.

Many barriers and enablers to accessing quality palliative care in Australia may be universal—i.e. they are relevant to the Australian population as a whole. However, these are likely to be magnified for the under-served populations identified, and additional, more specific challenges may also be faced by individuals and service providers.

This chapter highlights:

- Barriers and facilitators that are either universal or common to most or all of the identified under-served populations

- Underpinning enablers of high-quality palliative care for these groups

- The potential role of advance care planning in improving the delivery of appropriate palliative care.

These findings inform the high-level recommendations for improving access to and quality of palliative care for all under-served populations provided in *Chapter 4*.

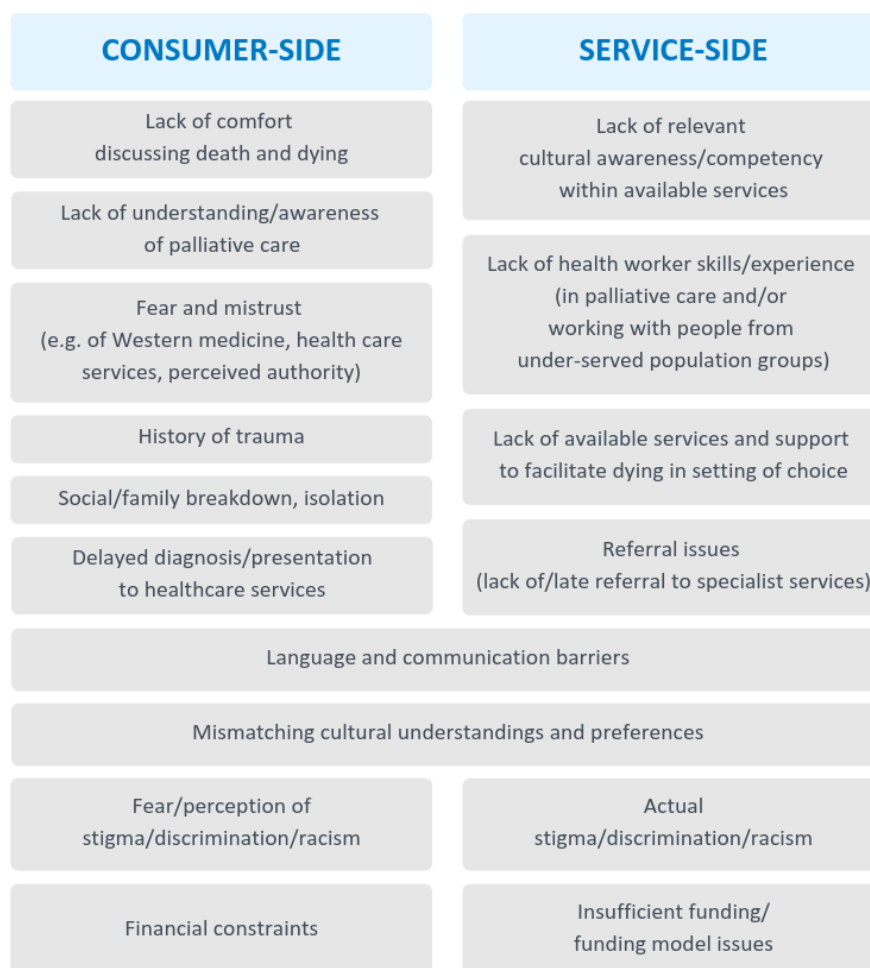# Common themes: barriers and promising approaches

A number of common barriers, relevant to all under-served population groups, were identified throughout the project and are summarised in *Project findings*. Enablers and promising approaches described addressed one or more of these barriers.

They are categorised here (as well as throughout the associated issues reports) as consumer-side (relating to individuals, families and communities) and service-side (relating to health professionals, service providers and other organisations and the healthcare system more broadly).

These categories are not intended to lay fault for barriers (or responsibility for facilitators) on one particular side of the palliative care relationship, but rather to provide a framework within which to consider appropriate service system responses.

The ways and extent to which the identified universal or common themes affect each population group identified in the project are highlighted in individual issues reports (see *Appendix A* for a summary of key messages).

Figure 3-1: Universal and common barriers to quality palliative care for under-served population groups

CONSUMER-SIDE	SERVICE-SIDE
Lack of comfort discussing death and dying	Lack of relevant cultural awareness/competency within available services
Lack of understanding/awareness of palliative care	Lack of health worker skills/experience (in palliative care and/or working with people from under-served population groups)
Fear and mistrust (e.g. of Western medicine, health care services, perceived authority)	
History of trauma	Lack of available services and support to facilitate dying in setting of choice
Social/family breakdown, isolation	
Delayed diagnosis/presentation to healthcare services	Referral issues (lack of/late referral to specialist services)
Language and communication barriers	
Mismatching cultural understandings and preferences	
Fear/perception of stigma/discrimination/racism	Actual stigma/discrimination/racism
Financial constraints	Insufficient funding/ funding model issues

One way of articulating the key themes common among under-served populations is to describe the facilitators required to support people from these groups through an ideal palliative care 'journey'. These elements are summarised in *Figure 3-2* and discussed in detail below.

Theoretically, to achieve best-practice person-centred palliative care, the following elements would be in place:

- Individuals, families, communities and health and social care providers are able to proactively discuss issues surrounding death and dying and have a general awareness of palliative care concepts and available services (i.e. **increased community comfort discussing death and dying** as well as **awareness and understanding of palliative care)**

- For individuals with life-limiting illnesses, current and future palliative care needs are considered early to allow **timely referral/initiation of palliative care** as well as evolving conversations around need

- Individuals and families are supported in conversations about palliative care, dying and death, and made aware of the options available in changing periods of need (i.e. appropriate **information provision and communication** between individuals/families and health and social care providers)

- Palliative care providers:

  – **Understand under-served population groups** and their potential needs and challenges, while ensuring that each individual's unique experiences, needs and preferences are understood

  – **Deliver person-centred care**— i.e. flexible care in appropriate settings.

'All initiatives need a patient-focused, "whole-of-journey" approach, taking in barriers and facilitators to high-quality care'
—Academic

Figure 3-2: Facilitating an ideal palliative care journey

NEEDS		
Individuals, families and communities	**Health and social care providers**	**Specialist palliative care providers**
Increased comfort with discussing death & dying generally (more relevant for some than others)	Increased comfort with discussing death and dying (in general and with members of under-served populations)	Increased comfort with discussing death and dying (particularly with members of under-served populations)
Greater awareness and understanding of palliative care		
	Broad understanding of under-served population groups, without cultural stereotyping	
	Early identification of an individual's need and initiation of palliative care discussions and delivery (either directly or via referral)	
	Increased capacity to provide or support palliative care (including knowledge of the options and supports available)	
Appropriate information provision and communication (e.g. at point of diagnosis and/or palliative care need and throughout service delivery)	Support to communicate effectively and appropriately with individuals from under-served populations	
Confidence in services' and service providers' ability to provide acceptable and appropriate palliative care	Ability and willingness to provide flexible, appropriate, person-centred palliative care	
Financial support to access appropriate palliative care (e.g. community supports)	Appropriate remuneration/funding models to support person-centred palliative care provision	

Increasing comfort with discussing death and dying

While there may be a general culture of 'death denial' in mainstream Australian culture,[8] for some under-served populations, a **reluctance to talk about death and dying** represents an even stronger barrier to accessing palliative care, and having specific needs met when it is accessed. For example, these topics may be considered 'taboo' in some cultures, or personal experiences with death and dying may be more likely to be traumatic among some population groups.

Even healthcare professionals whose core business includes the management of life-limiting illnesses may find it difficult to initiate conversations about palliative care,[34] and this may be magnified when caring for people from under-served population groups. Even for specialist palliative care providers, well used to discussing death and dying in a professional yet empathetic manner, the nuances of discussing issues related to palliative and end-of-life care with those from under-served populations may be daunting and challenging.

'How can we expect under-served populations to engage in these conversations if health professionals find it hard?'
—Stakeholder workshop participant

Whole-of-population efforts aimed at normalising these conversations (e.g. Groundswell,[i] Dying to Talk[ii]) are likely to have a trickle-through effect for individuals, communities and health and palliative care providers—and there are also efforts within specific population groups to target these challenges (see issues reports for examples).

Community awareness and understanding of palliative care

In general, and across all the identified under-served population groups, a **lack of understanding of what palliative care is**, how it could help, which health and social care providers are involved and what services are available was reported.

While community awareness and understanding of palliative care was found to be low, it is important to note that individuals' understandings, in most instances, were shaped by personal experiences. Community members spoke about family members', friends' and acquaintances' journeys through palliative care settings in both positive and negative terms. People's assumptions and misconceptions (e.g. about the settings in which palliative care is delivered, when it is provided, and by whom) were directly linked to their interactions with the sector throughout their lives.

It is perhaps unsurprising, then, that many people held the view that palliative care is provided in hospitals and hospices by specialist providers, or in residential aged

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[i] https://www.thegroundswellproject.com/
[ii] https://dyingtotalk.org.au/

care settings by staff, and only in the final weeks or days of a person's life.

The concept of palliative care being about quality of life, rather than end-of-life, was not well understood by the members of under-served communities consulted and, in some cases, the term was either associated with assisted dying (whether voluntary or not) or as a poor alternative to assisted dying for those experiencing significant pain and suffering at end-of-life (i.e. unnecessarily prolonging suffering).

> *'I think we shouldn't let people suffer unnecessarily'* —CALD community member

> *'I wouldn't do that to a dog'* —Community member affected by forced adoption

> *'The needle comes out and people are quietly euthanised. It happens all the time'* —LGBTI community member

This was in direct contrast to service providers' perspectives; these stakeholders were keen to clearly separate and differentiate palliative care from voluntary assisted dying.

> *'Communication is key—there is a need to put palliative care in language that doesn't frighten people'* —Stakeholder workshop participant

> *'[Palliative care] is about letting people live well until they die'* —Service provider

Community engagement and education regarding palliative care is occurring in a number of population groups, particularly through PCA state and territory member organisations and their collaborative work with community organisations. However, it may not be reasonable to expect a large proportion of the community (and perhaps in particular members of under-served populations) to be interested in the subject of palliative care before a personal need arises for them or a loved one. In addition, education about what palliative care options might be available may be unhelpful if people's actual experience does not reflect the ideal (e.g. if community care is unaffordable, if a person's condition is too complex to be managed at home, if primary care physicians are not discussing and initiating palliative care early, etc).

However, as trends in the palliative care sector shift (e.g. from hospital and hospice settings to broader community settings) the experiences—and therefore understandings—of all Australians are likely to broaden to be more inclusive of different settings, care providers and timing of palliative care discussion and provision.

A more powerful way of improving community awareness and understanding, therefore, may involve a focus on ensuring health and social care providers and others in direct contact with individuals and under-served population groups are up-skilled in understanding relevant concepts in palliative care as well as what care delivery options and supports are available (see p.36).

> *'We demystify what [palliative care] is, we demystify it for health professionals so they can inform people in the community who think it's just about the dying'* —Palliative care education provider

Timely initiation of palliative care

One key area of misunderstanding—reported to exist among healthcare consumers as well as health and social care providers *not* involved in the delivery of palliative care—was the place and role of palliative care in the continuum of care. It was felt that many in the healthcare workforce perceived palliative care and active treatment as mutually exclusive, rather than as complementary components of best-practice care.

'Palliative care is poorly understood by the community—even among professionals who don't work in the area'
—Stakeholder workshop participant

'It needs to be seamless—at the moment, you are either "palliative" or you're "normal"' —Stakeholder workshop participant

From the service side, **lack of—or late— referral or initiation of care** was often raised as a key barrier to effective palliative care for under-served populations.

While this was felt to be true across the board, a number of the population groups explored were noted to typically present to healthcare services in general in a later/more advanced stage of disease. Compounding this:

- The particular and often more intensive, complex or difficult-to-meet needs of members of under-served population groups mean that early consideration of palliative care needs may be even more vital. This may include considering likely future needs as well as multidisciplinary/multi-sector input.

- Health and social care providers may be less likely to consider palliative care need for those with a non-cancer diagnosis (e.g. other chronic illness, dementia).

- Palliative care need (or need for escalation of palliative care) may be more difficult to recognise in individuals from a number of under-served populations, for example because of diagnostic 'overshadowing'[iii] in the context of those living with a disability, or prioritisation of more urgent health and social needs for those experiencing homelessness.

- Trusted relationships are vital in the provision of palliative care, but may not exist (e.g. with primary care providers), take longer to develop, or be more difficult to achieve with members of under-served populations.

Standard practices and **automatic referral processes** (e.g. at point of diagnosis with a life-limiting illness) may overcome some of these barriers, as they can ensure palliative care discussions begin early with all patients and discussions and services can be 'ramped up' as needs progress.

[iii] A 'phenomenon in which a person's presentation is attributed to their underlying condition…potentially delaying identification of other problems and referral to hospice and/or palliative care'.[55]

'[Program of Experience in the Palliative Approach] training delivers the message that palliative care can be commenced at the time of diagnosis of renal disease, dementia, etcetera'
—Peak body representative

As palliative care is intended to be delivered primarily in non-specialist settings, improving the capacity of this workforce to provide palliative care, and increase awareness of available supports (including access to specialist advice, community support services etc) is of particular importance. For many under-served populations, a **'no wrong door' approach** is likely to facilitate timely access to palliative care. Such an approach includes upskilling in relevant settings including primary care, aged care, disability care, and other community care settings to recognise and act upon new palliative care needs.

Understanding under-served populations

It is not feasible to expect all health and social care providers to have comprehensive understanding and experience working with all the identified under-served (and other vulnerable) population groups.

In addition, **diversity** within each of the population groups explored, and **crossover** among them, are very important considerations. These key issues were acknowledged at the outset of the project and continuously reinforced through the literature, consultations with organisational stakeholders and conversations with members of under-served population groups.

For example, it is noted in the literature that most Australians wish to die at home, and that members of some population groups may have an even stronger preference—if not a cultural imperative—for home-based end-of-life care. However, such a preference should not be assumed.

Despite the generalities highlighted in the literature (including the nine issues reports developed from this project)—**cultural stereotyping** (relating not only to CALD groups but all of the population groups explored in this project) should be acknowledged and actively avoided. While it may be useful to be aware of general cultural considerations, such awareness is best used as a starting point from which to consider—and ask about—the extent to which an individual's needs and preferences align or differ from pre-conceived generalisations.[35]

However, as highlighted throughout this document, the identified under-served populations are likely to experience numerous barriers to healthcare and other services throughout their lives.

'We know that people who have an advantaged life have an advantaged death'
—Academic

Awareness of trauma-informed approaches to care

There is increasing recognition that many individuals have 'extensive histories of trauma that, left unaddressed, can get in the way of achieving good health and wellbeing'.[15] Given the significant exposure to trauma in the general population, in the ageing population, and in those with life-limiting illness, a recent review suggests 'an overall need for hospice and palliative care to be trauma-informed',[16] even before taking into consideration the needs of more specific populations such as those included in this project.

'Everyone is vulnerable at the end-of-life' —Palliative medicine physician

Despite its likely relevance in the palliative care setting, familiarity with, and understanding of 'trauma-informed approaches' varied widely among the (service-side) stakeholders consulted throughout this project.

Many stakeholders felt it was merely an articulation of one consideration in the provision of **person-centred care**, and therefore represented 'core business' for palliative care providers. While others felt that it may be out of scope, or actively avoided by health and social care providers in the palliative care context, this view often related to a belief that trauma-informed approaches were aimed at directly addressing and/or treating the effects of trauma, rather than a more universal approach that recognises these effects may exist and have implications for the provision of care.

> *'We don't focus on trauma-informed care—it's just person-centred care' —Stakeholder workshop participant*

On the other hand, organisations working with particular population groups (notably those experiencing homelessness, people who are incarcerated, veterans, and care leavers and those affected by forced adoption) were well aware of the principles and practice of trauma-informed care.

Generally, the project found that 'skilful awareness' of the likelihood of psychological trauma[16] and universal trauma-informed approaches (see p.12) are likely to benefit all palliative care clients, but particularly those affected by trauma.[23]

> *'What do I need to know about you as a person, in order to take good care of you?' —Stakeholder workshop participant*

> *Talking about past experiences can be psychologically beneficial in the right circumstances. However, the knowledge that the patient may have endured certain experiences due to their country origin or transit is generally sufficient for you to orient your care —Australian Refugee Health Practice Guide[36]*

Information provision and communication

Effective, appropriate and sensitive information-sharing is required throughout a person's palliative care journey. This information-sharing may be achieved through conversations between individuals/families and palliative care (and other health and social care) providers, written resources, websites, podcasts, videos, apps and any other channel (and any other language) that is appropriate.

'Palliative care communication is very different to everyday communication. We need to help people find hope, cope with grief, address their spirit, and plan for tomorrow' —Government representative

As well as increasing health and social care providers' comfort and proficiency in discussing palliative care (in particular with those from under-served populations), this may also involve providing (or facilitating the provision of):

- Information using appropriate language (and languages) and in different formats

- Specific information regarding local palliative care services, options and entitlements

- Individual support to help people and families navigate the relevant system(s).

Palliative care providers and those in a position to refer individuals to palliative care services should be supported in providing this information (e.g. through training and professional development, and access to a range of communication resources and supports). In discussing palliative care with people from under-served population groups, additional support may be required to ensure discussions are effective, appropriate and sensitive.

Provision of person-centred palliative care

Person-centred care may be the most effective way of facilitating, as far as possible in individual circumstances, good quality of life for those with a life-limiting illness and, ultimately, a 'good death'—as defined by individuals, families and communities[37]—through holistic end-of-life care.

Information provision and communication (see earlier) is a necessary precursor to person-centred care. For example, observed discrepancies among patient, family member and healthcare professional perspectives of a good death 'indicate a critical need for a dialogue about death among all stakeholders involved in the care of each individual patient' that presumably is equally important in broader aspects of palliative care.[37]

However, person-centred care is not easily defined, let alone provided, and the complexity of the service delivery system (including palliative care, other healthcare, community support services and other sectors) means there may be a **lack of accountability** for facilitating it. Stakeholders also noted some concerns with the concept of person-centred care, particularly as it relates to some members of under-served populations.

'We need to take a critical look at the concept of person-centred care. What does it mean for these populations of interest, many of which have limited agency, limited awareness or experiences of choice' —Palliative medicine physician

This echoes the critique of person-centred care and consideration of the concepts of family- and relationship-centred care (see p.15). However, a **lack of trust** noted across the identified under-served populations (e.g. of health services, of authority, of governments and government-funded services), coupled with a **lack of time for relationship-building—**and sometimes broader issues of isolation from family and society—significantly hinders service providers' ability to provide such care for people from these population groups.

While '**culturally-appropriate care**' is often suggested in the context of under-served population groups, interpretation of the term often 'views culture as static and unchanging', 'fails to account for diversity within groups', and leads to 'stereotyping and a failure to identify the needs of the individual receiving care'.[35]

In order to accommodate the great diversity of Australian people, and their needs and preferences relating to palliative and end-of-life care, it may be most important to shift from providing *special* care to people belonging to under-served populations to instead providing *inclusive* care to *all* people, including those from these groups.[38]

'We need to have a palliative care service that is inclusive for all groups, not a different service for different populations, but to do this we need to identify barriers and facilitators' —Stakeholder workshop participant

'If we truly had patient-centred care, we wouldn't have these particular groups being under-served' —Government representative

Despite these challenges, for individuals and communities, 'seeing' services that are relevant to and appropriate for people 'like them' (e.g. through experiences with loved ones) is likely to engender **confidence and trust** in those services. This represents the removal of a key barrier to accessing palliative care, especially for under-served populations.

In practice, person-centred care is likely to involve **flexible and holistic care options** delivered in **appropriate settings**. In particular, building capacity for community-based palliative care options is of particular importance.

> *'We need to consider where the person wants to live, not just what's convenient for us' —Service provider*

Many other suggestions relating to improving flexibility of care (and funding models to support this) were highlighted throughout the project, including, for example, providing support for transport to/from palliative care services and developing/utilising telehealth options to remove barriers to access where relevant, and facilitating cultural practices and aspects of care in mainstream services.

For under-served populations, **trauma-informed approaches** may also assist service providers in providing person-centred care (see pp.11-15).

While person-centred care aims to fulfil a person's needs and preferences, it is important to acknowledge that it may not always be possible to provide palliative care that matches these preferences. The Standards note that where care cannot be delivered in accordance with an individual's goals and preferences, this should be discussed with the person, their family, and carers, and an agreed alternative plan documented and communicated.[4]

'There needs to be a systems-based approach to improve choices. There is no point asking clients about choice if we can't deliver' —Academic

Palliative care in rural and remote settings

While rural and remote population groups were not identified as a focus for this project, many stakeholders noted the particular issues in providing quality palliative care (including geographical challenges and variations in service delivery) in non-metropolitan settings.

'The level of services varies dramatically in geographically remote areas. Our metro areas are well covered, our regional less so, and remote is "hit and miss". All people should be able to have the same access' —State government representative

'In the country, resource constraints are quite severe, not just for services but for clients as well' —Service provider

'The challenge is that the services [in remote areas] are general and broad—there is a lack of specialist services'
—Peak body representative

'Remoteness shouldn't be a barrier to accessing good support and care—if we can tie our workforce together then we start to provide more services and care' —Peak body representative

'We need to recognise that in rural areas there can be an absolute lack of palliative care services, let alone the ability to provide choice'
—Stakeholder workshop participant

While the relative lack of services in rural and remote areas is acknowledged, it is uncertain whether inequalities in access to care are any greater in these settings.

'There is as much inequality in access to palliative care [for under-served populations] in the metropolitan area as there is in regional and rural areas'
—Government representative

Innovative approaches to palliative care provision, including the use of **telehealth** or **specifically-designed apps** (for health and social care providers) was a suggested strategy to bring not only palliative care expertise, but also better understanding of under-served populations, to communities that may be smaller, more isolated, and/or more poorly-resourced.
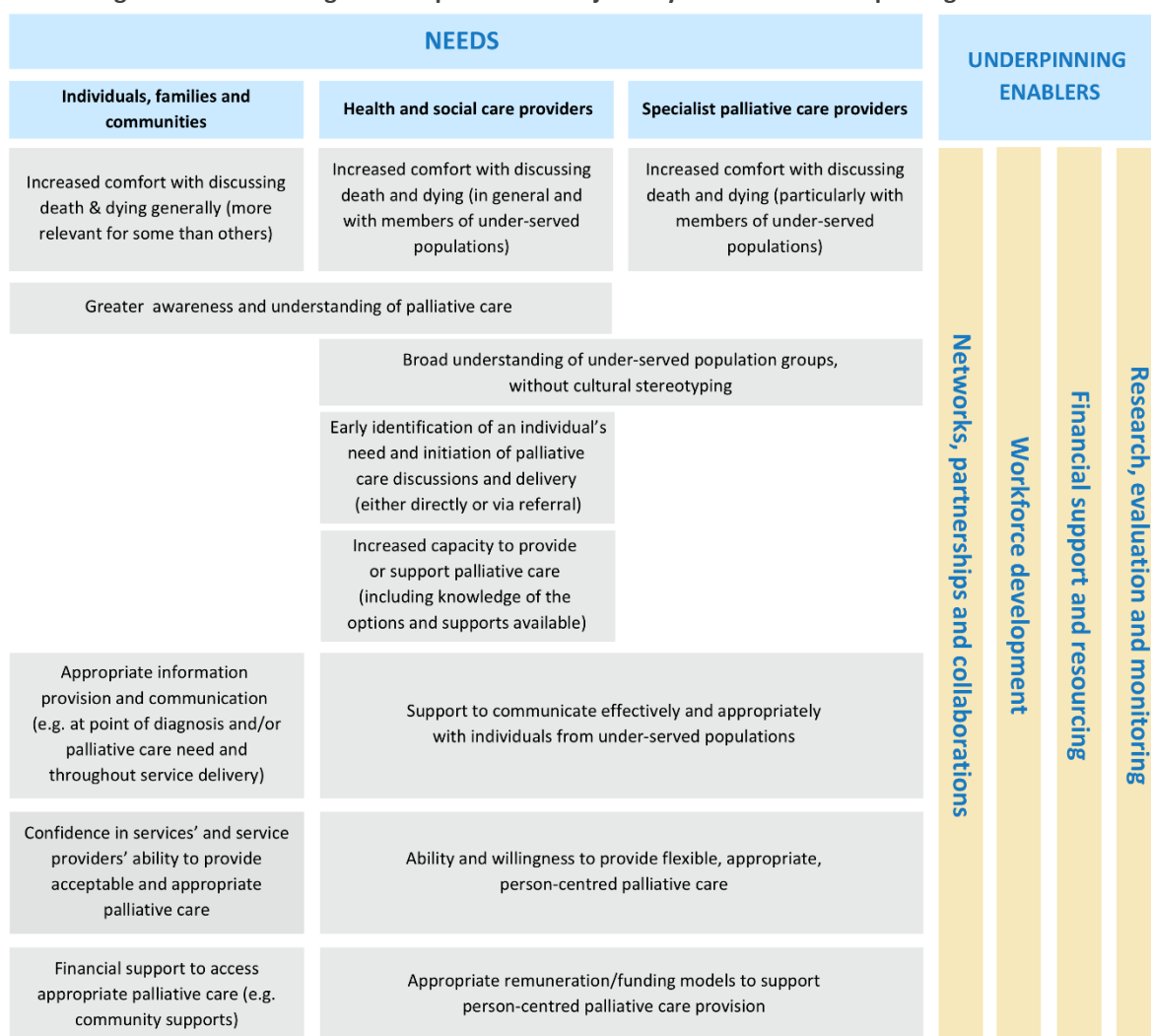
Underpinning enablers

While the previous section describes a number of domains facilitating appropriate palliative care, these are underpinned by four key enablers:

• Networks, partnerships and collaborations

• Workforce development

• Financial support and resourcing

• Research, evaluation and monitoring.

These elements are essential across all stages of the palliative care journey and vital in supporting **capacity-building** within relevant sectors including palliative care, primary care, aged care, and organisations representing and working with under-served populations.

Figure 3-3: Facilitating an ideal palliative care journey: needs and underpinning enablers

NEEDS			UNDERPINNING ENABLERS
Individuals, families and communities	**Health and social care providers**	**Specialist palliative care providers**	
Increased comfort with discussing death & dying generally (more relevant for some than others)	Increased comfort with discussing death and dying (in general and with members of under-served populations)	Increased comfort with discussing death and dying (particularly with members of under-served populations)	Networks, partnerships and collaborations — Workforce development — Financial support and resourcing — Research, evaluation and monitoring
Greater awareness and understanding of palliative care			
	Broad understanding of under-served population groups, without cultural stereotyping		
	Early identification of an individual's need and initiation of palliative care discussions and delivery (either directly or via referral)		
	Increased capacity to provide or support palliative care (including knowledge of the options and supports available)		
Appropriate information provision and communication (e.g. at point of diagnosis and/or palliative care need and throughout service delivery)	Support to communicate effectively and appropriately with individuals from under-served populations		
Confidence in services' and service providers' ability to provide acceptable and appropriate palliative care	Ability and willingness to provide flexible, appropriate, person-centred palliative care		
Financial support to access appropriate palliative care (e.g. community supports)	Appropriate remuneration/funding models to support person-centred palliative care provision		

Networks, partnerships and collaborations

With the wide range of services providing and supporting palliative and end-of-life care, service fragmentation is a key challenge in providing quality, person-centred care for all Australians with a life-limiting illness.[39]

Given the diversity of under-served population groups and the individuals within them, networks, partnerships and collaborations are vital to supporting all Australians in the promotion and provision of quality palliative care. Such collaborations can help to break down the silos apparent in current service delivery to achieve a number of the recommendations highlighted in this document, from raising community awareness through to providing person-centred care. They support a 'no wrong door' approach to enable individuals to access the most appropriate services at the most appropriate time.

'We need to accept that we don't know everything, but we are willing to learn and link with others'
—Palliative care education provider

At one level, these networks, partnerships and collaborations might simply **facilitate clear referral pathways** to ensure early access to specialist palliative care services—or advice—when needed, and smooth transitions between sectors and settings. However, in providing holistic care for under-served population groups, these

pathways may include a number of other specific support services and/or community organisations.

'We need to open doors across services and consider "our patients", not "my patients"'
—Government representative

Stakeholders also highlighted the need for more **proactive approaches** (e.g. outreach and in-reach services) to promote access for those who are most hard-to-reach, although organisational capacity to do this is currently constrained.

'Collaboration is essential to ensure that people involved in palliative care are communicating and sharing information, and that those affected by life-limiting illnesses have a seamless experience of palliative care wherever and however they are being supported'
—National Palliative Care Strategy 2018

Palliative care providers may also need assistance from those with a greater understanding of the needs of different population groups in order to co-design services and optimise person-centred care.

It is not feasible to expect all palliative care providers to have expert knowledge of, and experience with, all population groups (see p.26). Similarly, those who are members of, or have extensive experience with individual population groups can't be expected to be experts in palliative care. Linkages and networks between sectors, however, can help palliative care providers and recipients of care bridge the gap in order to get the best of both worlds. Community organisations and population-specific 'support organisations'—i.e. those with existing relationships and experience meeting the needs of each group—are likely to be of particular importance in this regard (see *Figure 3-4*).

Figure 3-4: Bridging the gap: networks, partnerships and collaborations
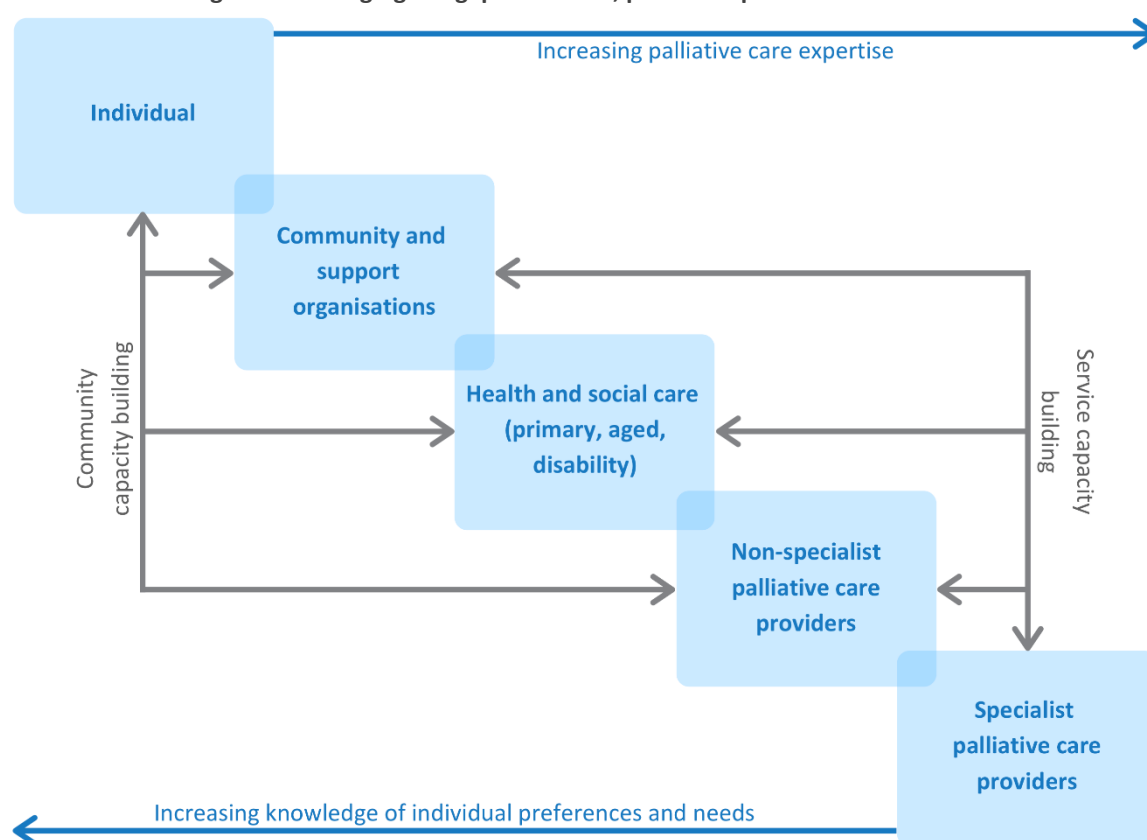
'**Reciprocal consultation**' describes 'the process of sharing expertise across disciplines in order to improve service provision'.[40] This process of exchange of information and expertise can enable a service provider to better meet the needs of an individual, rather than providing 'standard' care or referring elsewhere. Reciprocal consultation may take place on an 'as needed' basis, as long as the relevant networks and relationships are in place.

The role of community members in service improvement and co-design can be conceptualised similarly. The input of healthcare consumers in service co-design may be considered an element of person-centred care.[41]

'Community consultation is a reciprocal process and a genuine partnership between the community and a service provider that embodies human rights principles in a tangible way' —Centre for Refugee Research, UNSW.[42]

In efforts to bolster community awareness and understanding of palliative care, networks, partnerships and collaborations are needed between *all* relevant sectors to reach under-served population groups. The identification and training of **'community champions'** (for palliative care and advance care planning) was often noted throughout the project as a potentially successful strategy for effective **community engagement**.

'The how of community capacity-building involves looking for "linking assets" that can bridge between health networks and community networks' —Academic

These sentiments fit well within a public health approach to palliative care (see p.11).

The potential scope of these networks, collaborations and partnerships is broad, as they should exist across the patient journey (i.e. from community comfort in discussing death and dying and awareness and understanding of palliative care through to the provision of person-centred end-of-life care). Even more generally, they can be used to improve the other underpinning enablers described—i.e. workforce development, funding and resourcing, and research, evaluation and monitoring.

Figure 3-5: Broad and innovative networks support person-centred care

Novel and innovative partnerships and networks may be required to reach and engage, as well as provide appropriate care for, under-served populations. Relevant partnerships will depend on local context, but may include those highlighted in *Figure 3-5*, as well as others.

However, in the specific context of improving palliative care access and delivery for under-served populations, it is perhaps the linkages between palliative care providers, other support service providers, staff within key settings (e.g. primary care, aged care, disability support etc.) and organisations representing or working with each group that are most relevant.

Workforce development

Workforce development is a key theme for improving the palliative care journey. It has the potential to affect all of the 'touchpoints' between a patient and their family and palliative care services.

Many stakeholders noted an under-supply of specialist palliative care professionals in the workforce, meaning that the sector had limited capacity for additional efforts to focus on under-served population groups. This was compounded by a lack of palliative care training and experience among other health and social care providers.

Overall, the project highlighted the need to increase and improve the delivery of palliative care by non-specialist providers, and increase understanding and awareness of palliative care among health and social care providers not directly involved in its provision.

Greater **education and training** regarding palliative care for all health and social care providers, starting at the undergraduate level and continuing with ongoing professional development activities, was considered important, and stakeholders noted that resources to support this already exist (e.g. the Palliative Care Curriculum for Undergraduates (PCC4U[iv]) and the Program of Experience in the Palliative Approach (PEPA[v]). Utilisation of such workforce development approaches must be supported by relevant **organisational structures and systems including policies, protocols and funding arrangements**.

> '*All health professionals who provide care to people living with a life-limiting illness, their families and carers should have minimum core competencies in the provision of palliative care*' —*Palliative Care Service Development Guidelines*

As noted in the discussion of a public health approach to palliative care (see p.11), community settings (including primary care, residential aged care, disability community living etc) are of particular importance in this respect, and the development of these workforces is likely to be a priority in order to facilitate access to and provide person-centred palliative care to those already within or connected to these systems. In particular, residential aged care has been identified as an important but challenging setting for the delivery of palliative care, given the high prevalence of chronic disease and comorbidities among residents.[43] The Australian Government's *Better Quality of Care—comprehensive palliative care in aged care* measure[44] is aimed at addressing

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[iv] http://www.pcc4u.org/

[v] https://pepaeducation.com/

palliative care access and delivery in this important setting.[vi]

For the benefit of under-served populations specifically, workforce training and development could help healthcare and other support providers better understand the needs of people from these groups. This includes cultural competency and/or inclusiveness and education related to the potential effects of trauma and how **trauma-informed approaches** to care may assist in the design and delivery of palliative care services. Where appropriate, training should be informed by (and, where possible, delivered by) those from under-served populations or with relevant lived experience.

A **more diverse and inclusive workforce** in key settings (palliative care, primary care, aged care, disability etc) is also likely to improve the inclusiveness of services. Recruitment of staff from under-served population groups (as appropriate) and/or employment of diversity officers or champions within palliative care and other relevant services were considered important workforce strategies to address issues of access and appropriateness of care for under-served population groups.

'There is a need to diversify the workforce'
—Government representative

Financial support and resourcing

Affordability is an issue in providing flexible care, and this relates both to out-of-pocket expenses for patients and their families as well as remuneration for services providing care. Given the often vulnerable and socioeconomically disadvantaged nature of the under-served populations identified, the personal **financial cost** of palliative care and associated support (e.g. medicines, equipment, respite)—especially for care within the community—may be prohibitive.[45]

A general **lack of services, equipment and support**—especially for community-based palliative care—was also reported by many stakeholders, and is a challenge that was considered magnified in rural and remote areas (see p.31), particularly for those with specific needs.

On the other side of the equation, palliative care service representatives often reported that they were 'already stretched', with **little capacity** to seek out those not proactively accessing their services. Individuals from under-served populations may have more complex needs than other patients in the palliative care context, and holistic care may therefore be more time- and resource-intensive. In particular, case management or other **support to navigate services** might be of great assistance to individuals, but not feasible without dedicated funding.

> *'Our capacity to provide palliative services and support for people to die in their own homes is a challenge'*
> *—Peak body representative*

[vi] Comprehensive discussion of barriers and enablers to delivery of palliative care in residential aged care settings are outside the scope of this project. For more information on this topic, see Palliative Care Aged Care Evidence (palliAGED): https://www.palliaged.com.au/tabid/4248/Default.aspx

'It's about case management. We can solve these problems if we have someone that can do the coordination' —Service provider

As illustrated in *Figure 3-3*, **funding models** support the provision of person-centred palliative care, wherever it is best delivered and among populations with potentially limited capacity to pay for private services and supports. These models should support integration and smooth transitions between palliative care and other settings and funding streams (e.g. disability, aged care).

However, the existing 'siloed' funding models were often highlighted to be barriers to access to palliative care and sources of frustration for service providers and community members. At the broadest level, the responsibility for palliative care can be difficult to delineate between Australian Government and state/territory funding models.

'While Governments have recognised community concern about end-of-life care, progress is being hindered by poor stewardship, including conflict over responsibilities and how service provision is coordinated across different settings' —Productivity Commission.[6]

However, stakeholders more particularly noted challenges relating to transitions between settings and funding models. For example, difficulties can arise in transitions to palliative care from:

- Activities funded through the National Disability Insurance Scheme (NDIS)—especially navigating transitions in and out of acute care settings

- Aged care—e.g. where the allocation of additional funding for palliative care provision is dependent on a definition of 'end-of-life' that refers to 'the last week or days' of life[46]

- Other service settings specific to individual under-served population groups.

'We should address the gaps between the palliative care sector, aged care sector and the NDIS' —Stakeholder survey respondent

'Systems are designed to keep people out' —Stakeholder workshop participant

In the primary care setting, while existing items can be used for advance care planning,[47] **a lack of palliative care or advance care planning-specific Medicare Benefit Schedule (MBS) items** was cited as a potential barrier to the provision of such activities.

Research, evaluation and monitoring

Although not raised frequently in stakeholder consultations, research, evaluation and monitoring activities have the potential (in the longer term) to improve all aspects of the palliative care journey for people from under-served populations. However, the identification of under-served populations in relevant datasets and information about palliative care delivery is currently lacking.

> *'Information about where Australians die, their preferred place of death and the end-of-life support they received is fragmented, because data are not standardised or collated into a single source'* —Australian Institute of Health and Welfare[48]

For example, it was recently noted, 'we know virtually nothing about [end-of-life] care in the Australian general practice setting'.[49]

> *'We don't have reliable data about the workforce, including volunteers. There would be value in doing a national workforce audit so we can work out how to address the gaps'* —Government representative

Given the increased emphasis on palliative care provision in non-specialist settings, **collection of data** (both qualitative and quantitative) regarding under-served population groups and the care provided in all palliative care settings will be important in improving governments' and service providers' understanding of population trends and needs as well as the appropriateness of service delivery responses.[50]

Given the increased emphasis on palliative care provision in non-specialist settings, data (both qualitative and quantitative) will be important in improving understanding of population trends and needs as well as the appropriateness of service delivery responses.

Some stakeholders noted the importance of including activities related to improving access and care for under-served populations in policies, standards and quality improvement processes in order to ensure these issues are considered in a meaningful, practical and ongoing manner.

Ensuring representation of under-served populations in palliative care-related research is also important in understanding communities' needs and preferences, as well as barriers to access and the quality of care provided.

> *'Invest in pilot programs where there are currently palliative care gaps: enable those without a voice to get involved more'* —Peak body representative

> *'There are some [services] who are thinking about [a public health approach to palliative care]. But there are no systematically-endorsed processes, for example, auditing requirements to ensure services look at population needs and provide linkages into community'* —Academic

Advance care planning

While Advance Care Planning Australia (ACPA) considers it 'a routine part of health and personal care', advance care planning—in particular the completion of statutory advance care directives—is not commonplace in Australian healthcare settings.[30] While it may be more prevalent among some population groups (e.g. those with a disability), it is reported to be lower among a number of population groups under-served in palliative care.

'Advance care planning in Australia is still quite aspirational' —Academic

Many stakeholders highlighted that while advance care planning may be very useful in providing person-centred palliative care, its scope and relevance is much broader. Palliative care is only one component of a wider concept of advance care planning (see p.18).

Despite this, providers of palliative care are often (at least theoretically) well-placed to initiate or continue advance care planning. The palliative care setting may be one of the easiest in which to 'sell' the concept to individuals and families, as there is often time, motivation and context in which to consider one's wishes and preferences for future care.

'Advance care planning is not the universal answer to person-centred palliative care, it's a conversation starter' —Stakeholder workshop participant

Many of the barriers that challenge access to palliative care also apply to advance care planning in the context of under-served populations. Again, while many of the barriers may be universal, these may be magnified for under-served populations. For example, a reluctance to talk about death and dying may be more prevalent in under-served populations than in others. The lack of responsibility for advance care planning in specific sectors or disciplines may be compounded by a lack of trusted relationships between members of underserved population groups and health and social care providers.

While the potential value of advance care planning was generally recognised, many under-served population groups face significant barriers—or are actively averse to—the more formal, legal outcomes of the process (i.e. ACDs). Reported issues include fear or mistrust (e.g. of healthcare services and providers, governments) and language, communication and literacy barriers.

'People with lower literacy find the [ACD] document terrifying' —Stakeholder workshop participant

While many stakeholders felt that advance care planning should occur well before the initiation of palliative care, this was expressed in the context of palliative care also being discussed and initiated too late in a patient's disease trajectory (see p.25).

If, as considered ideal, palliative care was introduced at the point of diagnosis with a life-limiting illness, then it is logical that support for advance care planning be embedded (although not exclusively) in that sector, keeping in mind the breadth of settings in which palliative care can be delivered.

'The ideal, going forward, is that people will engage [in advance care planning] earlier, and that will inform a whole range of things to do with palliative care'
—Peak body representative

Overall, increased capacity across sectors to support advance care planning is needed to improve its uptake among under-served population groups, so that the person or service with an existing relationship with an individual is in a position to assist. In this context, non-specialist palliative care settings may be most relevant (e.g. primary care, aged care, disability support), given the greater likelihood of a long-standing, trusted relationship along with knowledge of an individual's prognosis and likely disease trajectory.

'People think you're going to knock them off. You have to pick your moments'
—Hospital social worker

Specific support for the primary care sector to engage in advance care planning may be a useful strategy to pursue for all with a life-limiting illness.[6] As with palliative care, undergraduate training and ongoing professional development around advance care planning for primary care providers may be one element of such support, as would inclusion of advance care planning in other existing processes and funding models (e.g. the Health Assessment for Older Persons). Some stakeholders suggested that a lack of a specific MBS item to support advance care planning may mean that the role of primary care in this context was lacking visibility, or could act as a disincentive if health and social care providers perceive that they are not adequately compensated for the time taken for these activities. Greater awareness and appropriate remuneration (e.g. through a more specific MBS item) for primary care providers to facilitate these activities may help to overcome these barriers.[6,50]

Electronic records (in particular My Health Record[vii]) may represent a valuable repository for advance care planning documents, promoting their availability at relevant points of care (e.g. primary care, acute care, palliative care). However, significant challenges were noted by organisational stakeholders and community members, including concerns around privacy and mistrust of healthcare services and government authorities, for a number of the identified under-served populations.

[vii] https://www.myhealthrecord.gov.au/

In some settings, advance care planning can be—and in some cases is—embedded into organisational policy (e.g. on entry into aged care or correctional settings). However, the quality of such processes (i.e. the extent to which they are able to capture and cater for individuals' wishes and allow for preferences that may evolve over time) may be sub-optimal.

There have also been considerable efforts to communicate and engage with various communities around advance care planning, driven by ACPA, PCA member organisations and others. Tools have also been developed to help health and social care providers facilitate discussions with members of some under-served population groups, particularly Aboriginal and Torres Strait Islander peoples and those from CALD backgrounds.

'Advance care planning has to be a long conversation. To go on this journey takes time and resources'
—Stakeholder workshop participant

4 | Recommendations

This project identified seven domains that facilitate quality palliative care for all Australians (and particularly those from under-served population groups), underpinned by four key enablers (see *Chapter 4*). Recommendations arising from the project are framed in this context.

These domains and enablers are broadly consistent with the Strategy and other relevant policy documents. The recommendations in this policy paper reflect a public health approach to palliative care, which involves multiple sectors—from individuals and families to specialist palliative care service providers and broadly focused, 'non-traditional' partners and collaborators.

Although not a recommendation specifically arising from the project, current efforts to promote a public health approach to palliative care in Australia, including Compassionate Communities initiatives, should aim to maintain a focus on equity. This is necessary to ensure that under-served populations do not get 'left behind' while such strategies target less complex population groups that may be easier to reach and to care for. Otherwise, these initiatives may service to widen the gaps between under-served groups and the rest of the population.

The most important shift is from providing special care to people from under-served populations to providing inclusive care to all people.

Specific findings and recommendations relating to each of the nine identified under-served populations are summarised in the separate issues reports. Given the diversity within these groups (and others not included in this project), the most important strategy for improving access to palliative care is likely to be a shift from providing *special* care to people from under-served populations to providing *inclusive* care to *all* people, including people from these groups.[51]

These recommendations are designed to **bolster the capacity of all relevant sectors** to promote access to appropriate, quality palliative care for people from under-served populations who have a life-limiting illness. In particular, the idea of **person-centred care shines through as the ultimate goal** of all palliative care service provision. Person-centred care is respectful of, and responsive to, the preferences, needs and values of individuals.

It is important to acknowledge that identifying and providing the elements necessary to deliver person-centred care for people from under-served populations is likely to be particularly challenging and resource-intensive.

It is also important to recognise that implementing the recommendations in this report may require service providers and other organisations to make significant changes to organisational policies and procedures, structures and systems.

It is therefore vital that the underpinning enablers identified through this project—particularly workforce development and financial support and resourcing—are firmly in place. Without this support, efforts to improve access to quality, appropriate palliative care for under-served population groups are unlikely to succeed.

Person-centred care shines through as the ultimate goal of all palliative care service provision.

Addressing facilitators of appropriate palliative care for under-served populations

Increase community comfort with discussing death and dying

- Improve the comfort of all of society in discussing issues relevant to death and dying—including individuals, communities, and health and social care providers.

- Assist health and social care providers to improve their skill and confidence in talking about these issues with people from under-served populations.

Promote community awareness and understanding of palliative care

- Improve community understanding about palliative care, through broad social marketing strategies as well as specific efforts focusing on under-served population groups (e.g. education sessions organised through existing support groups, engaging community champions).

Facilitate timely initiation of palliative care

- Upskill health and social care providers and other relevant support people to identify when palliative care may be needed, engage in discussions with individuals and families and initiate or refer for care as appropriate.

- Consider introduction of standard palliative care-related practices and/or referral processes for all at time of diagnosis with a life-limiting illness.

Foster a greater understanding of under-served populations

- Ensure all health and social care providers are aware of and responsive to the potential impacts of the life experiences of under-served population groups—in particular the increased likelihood of trauma.

- Promote cultural understanding, while avoiding cultural stereotyping.

Improve communication and information provision

- Support effective provider–patient communication and the provision of appropriate information. For example, consider:

  – Information using appropriate language, in different languages and formats

  – Specific information about palliative care options and entitlements

  – Provide one-on-one support to individuals/families to navigate the relevant system(s).

Enhance provision of person-centred care

- Bolster communities' capacity to deliver palliative care that is flexible, individualised and delivered in setting(s) of choice where possible.

- Ensure appropriate setting design for under-served populations, including physical access, accommodation options, decoration/displays etc.

- Consider and respect the role of families (as defined by individuals) and communities in decision-making and person-centred care.

- Engage with under-served communities to co-design services.

- Ensure organisational policies, structures, systems and cultures are inclusive and support person-centred care.

Better support advance care planning

- Build on current approaches to enhance advance care planning among under-served population groups—particularly in specific settings such as primary care, aged care and disability services as well as palliative care.

- Support advance care planning through explicit inclusion in the Medicare Health Assessment for Older Persons as well as a new MBS item to remunerate health and social care providers in other contexts.

- Continue to explore opportunities for promoting consistency and mutual recognition of advance care planning documentation across Australian jurisdictions.

Addressing underpinning enablers

Networks, partnerships and collaborations

- Build capacity and resource support organisations to undertake a linking role with palliative care services, e.g. to:

  – Assist individuals to navigate services—including health care, palliative care, aged care and other services
  – Serve as a resource for palliative care services to understand the needs of under-served populations
  – Assist with broader awareness-raising in relation to palliative care and advance care planning within the communities they serve.

- Build linkages and reciprocal collaborations between all relevant sectors (e.g. palliative care and other health and social care services as well as support organisations) to develop referral pathways and best-practice approaches to palliative care service delivery for under-served populations.

Workforce development

- Mandate palliative care education and training in undergraduate health programs, especially medicine, utilising existing resources and supports (e.g. PCC4U).

- Consider other training and ongoing professional development initiatives that increase or improve health and social care providers':

  – Understanding of under-served populations
  – Understanding and ability to provide or support person-centred palliative care
  – Knowledge of and skill applying trauma-informed approaches

  – Comfort and capacity to assist individuals with advance care planning.

- Consider other initiatives to create a more diverse and inclusive palliative care workforce.

Financial support and resourcing

Noting that all recommendations in this document require appropriate levels of resourcing, more specific funding recommendations include:

- Ensure palliative care funding models are flexible to allow delivery of person-centred palliative care—recognising that meeting the needs of those from under-served populations may be intensive in terms of both time and resources.

- Improve the alignment of relevant funding systems (including NDIS, aged care, primary and other health care) to support seamless transitions.

- Fund community-based/population-specific approaches to palliative care, including establishment and maintenance of collaborative arrangements.

Research, evaluation and monitoring

- Consider appropriate research, evaluation and monitoring activities at all levels to understand the needs of under-served population groups and evaluate efforts to improve access for these groups.

- Include activities relevant to under-served population groups in palliative care quality assurance and improvement initiatives.

Abbreviations

Abbreviation	Definition
ACD	Advance care directive
ACPA	Advance Care Planning Australia
ACSQHC	Australian Commission on Safety and Quality in Health Care
AHA	Australian Healthcare Associates
CALD	Culturally and linguistically diverse
GP	General practitioner
LGBTI	Lesbian, gay, bisexual, transgender or intersex
MBS	Medicare Benefit Schedule
NDIS	National Disability Insurance Scheme
PCA	Palliative Care Australia
PCC4U	Palliative Care Curriculum for Undergraduates
PEPA	Program of Experience in the Palliative Approach
PTSD	Post-traumatic stress disorder
the Department	Australian Government Department of Health
the Standards	National Palliative Care Standards (5th edition)
the Strategy	National Palliative Care Strategy 2018
WHO	World Health Organization

Glossary

Advance care directive (ACD):

An advance care directive is a type of written advance care plan recognised by common law or specific legislation. An ACD can only be completed and signed by a competent adult. It may record the person's values and preferences for future care, and/or include the appointment of a substitute decision-maker to make decisions about health care and personal life management. Forms and requirements vary between states and territories.[52]

Advance care planning: The

process of planning for future health and personal care needs. It provides a way for a person to make their values and preferences known in order to guide decision-making at a future time when they cannot make or communicate their decisions.[53]

Care leavers: Includes Forgotten

Australians, Former Child Migrants and Stolen Generations.

Carers: People who provide personal

care, support and assistance to people with a disability, medical condition, mental illness, or frailty due to age. Carers may include family members, friends, relatives, siblings or neighbours. The term 'carer' does not include people who provide care for payment (such as a care or support worker), as a volunteer for an organisation, or as part of the requirements of a course of education or training.[54]

Compassionate Communities:

A palliative care framework that aims to promote and integrate social approaches to dying, death and bereavement in the everyday life of individuals and communities.[viii]

End-of-life care: Includes physical,

spiritual and psychosocial assessment, and care and treatment delivered by health and social care providers. It includes the support of family and carers, and care of the person's body after death. People are 'approaching the end-of-life' when they are likely to die within the next 12 months.[3]

Family: Includes people identified by the

person as family and may include people who are biologically related and people who joined the family through marriage or other relationships, as well as family of choice and friends.[9]

Life-limiting illness: Describes

illnesses where it is expected that death will be a direct consequence of the specified illness. The term incorporates the concept that people are actively living with such illnesses, not simply dying.[9]

Overshadowing: A 'phenomenon in

which a person's presentation is attributed to their underlying condition…potentially delaying identification of other problems and referral to hospice and/or palliative care'.[55]

Palliative care providers: Health and social care providers involved in the clinical management and coordination of care for people living with a life-limiting illness. Palliative care providers may include general practitioners (GPs), geriatricians, oncologists, physicians, paediatricians, renal specialists, cardiologists and other specialists. Other team members will include nurses, allied health professionals and pharmacists.[9]

Person-centred care: Care that is 'respectful of, and responsive to, the preferences, needs and values of patients and consumers'.[26]

Specialist palliative care services: Multidisciplinary teams with specialised skills, competencies, experience and training in palliative care. Care provided through these services is targeted at people with more complex needs, and is referred to as 'specialist palliative care'.[9]

Substitute decision-maker: A person appointed or identified by law to make decisions on behalf of a person whose decision-making capacity is impaired. A substitute decision-maker can be:

- Someone chosen (and appointed) by the person. Depending on the state or territory, they may be called an enduring guardian, a medical enduring power of attorney, an agent or a decision-maker.

- Someone assigned as a decision-maker for the person by law, in the absence of an appointed substitute decision-maker. The hierarchy for appointing a substitute decision-maker varies by jurisdiction. They may be a spouse or de facto spouse, carer, relative or friend.

- A substitute decision-maker appointed for the person (e.g. a guardian appointed by a guardianship tribunal).[52]

Trauma-informed care: 'An organisational structure and treatment framework that involves understanding, recognising and responding to the effects of all types of trauma'.[21]

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Appendix A. Key messages

The issues reports contain a 'key messages' summary of contextual information and population-specific barriers and promising approaches in relation to palliative care. These are reproduced in this appendix.

Each issues report also includes population-specific recommendations based on the framework described in this Summary Policy Paper (*Figure A-1*).

Figure A-1: Facilitators and underpinning enablers of quality palliative care
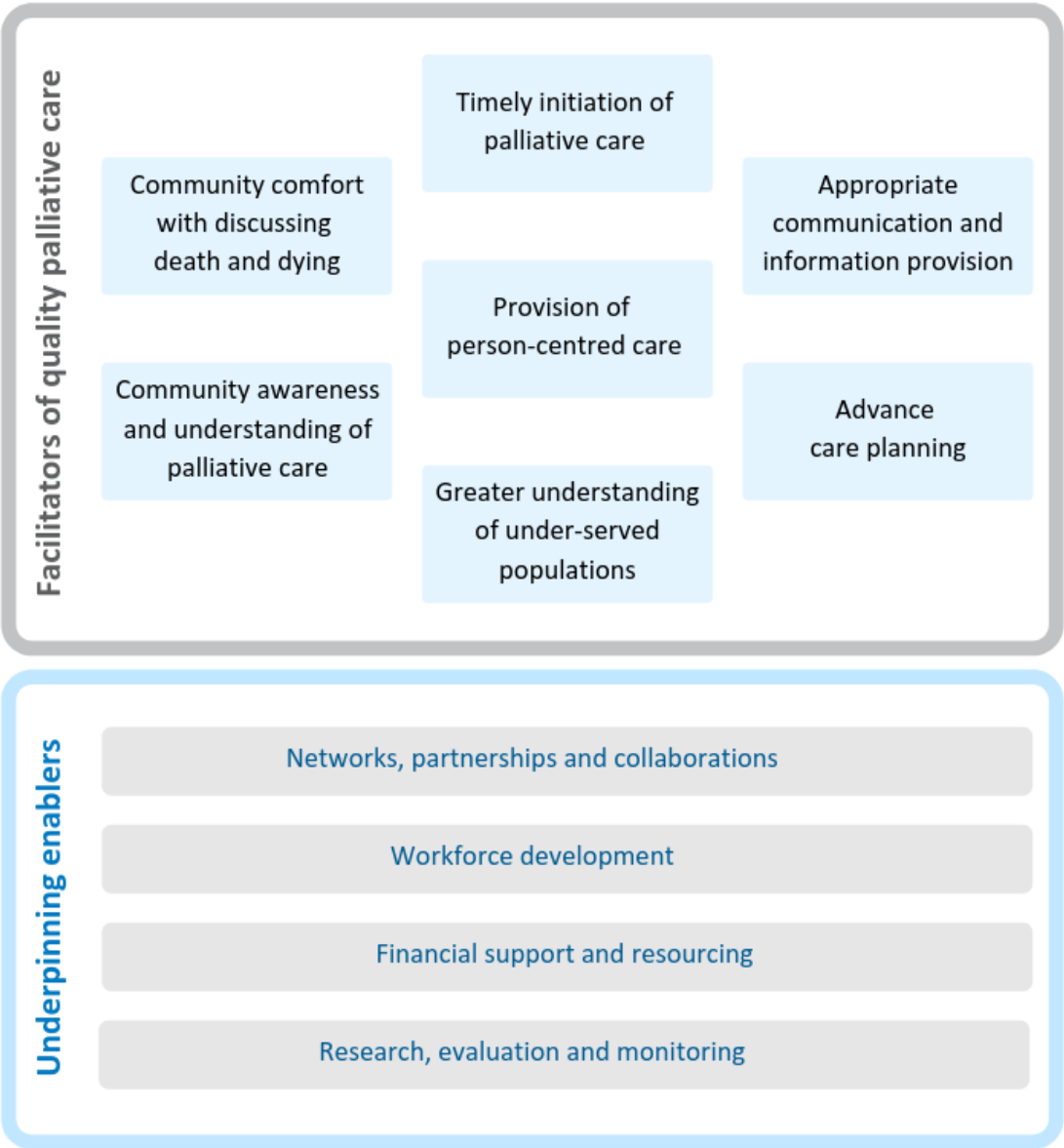
Aboriginal and Torres Strait Islander peoples

Considerable discrepancies in health and life expectancy mean that Aboriginal and Torres Strait Islander peoples experience the death of family and community members far more frequently than the non-Indigenous population. Aboriginal and Torres Strait Islander communities' history of dispossession, racism and systemic discrimination contributes to significant health disparities as well as barriers to healthcare access, and these factors may be of particular importance in the context of palliative and end-of-life care.

Key barriers and promising approaches for improving access to and experience of palliative care for this population group include:

Barriers

- Lack of awareness/understanding of palliative care
- Language and communication issues
  - Reluctance to talk about death and dying
  - Poor literacy/health literacy
  - Lack of translated, culturally-appropriate resources
  - Poor access to professional interpretation services
- Mismatching cultural, religious and/or health beliefs and preferences between individuals and service providers
- Fear or mistrust of 'Western' medicine and/or healthcare providers and services
- A preference for family-based or kinship-determined decision-making
- Difficulty accommodating cultural practices in palliative care settings
- Lack of/late referral to, or initiation of, palliative care
- Racism, discrimination (historical and current) and cultural stereotyping
- Financial disadvantage

Promising approaches

- Community awareness-raising
- Engagement between services and communities
- Culturally-appropriate and translated resources
- Culturally-appropriate engagement with individuals and families
- Access to appropriate professional interpreting services
- Training for professional interpreters (in palliative care concepts and terminology)
- Community capacity-building (for palliative care provision and support)
- Cultural competence within services
  - Education and training
  - Culturally-appropriate communication
  - Facilitating cultural elements and practices in service provision
  - Identification and inclusion of appropriate decision-makers
- Trauma-informed approaches to care
- Recruitment of Aboriginal and Torres Strait Islander staff
- Patient navigator initiatives

People from culturally and linguistically diverse backgrounds

People from culturally and linguistically diverse (CALD) backgrounds may experience a range of barriers to accessing and engaging with health and community support services in general, and palliative care in particular.

While CALD populations are, by definition, diverse groups of communities and individuals, culture plays a critical role in end-of-life needs and preferences.

Barriers and promising approaches for improving access to and experience of palliative care for this population group include:

Barriers

- Lack of awareness/understanding of palliative care
- Language and communication issues
  - Reluctance to talk about death and dying
  - Poor literacy/health literacy
  - Lack of translated, culturally-appropriate resources
  - Poor access to professional interpretation services
- Mismatching cultural, religious and/or health beliefs and preferences between CALD individuals and service providers
- Lack of/late referral to, or initiation of, palliative care
- Difficulty accommodating cultural practices in palliative care settings
- Community or individual fear or distrust of services
- Racism and discrimination, cultural stereotyping

Promising approaches

- Community awareness-raising
- Culturally-appropriate and translated resources
- Access to appropriate professional interpreting services
- Training for professional interpreters (in palliative care concepts and terminology)
- Community capacity-building (for palliative care provision and support)
- Improved cultural competence within services
  - Education and training
  - Culturally-appropriate communication
  - Facilitating cultural elements and practices in service provision
  - Identification and inclusion of appropriate decision-makers
- Recruitment of staff from CALD backgrounds and/or employment of diversity champions

Care leavers and people affected by forced adoption

While care leavers and people affected by forced adoption represent distinct groups with different issues and needs, the impact of traumatic life experiences for both groups contribute to barriers in accessing quality palliative care.

Barriers and promising approaches for improving access to, and experience of, palliative care for this population group include:

Barriers

- Lack of awareness/understanding of palliative care

- Distrust of the health system and government

- Health providers lack of understanding of impact of past experiences

- Impact of past trauma

- Challenging/dysfunctional family dynamics

- Lack of flexibility in institutional settings

Promising approaches

- Awareness-raising activities—including through existing support groups

- Education and training for health and social care providers

- Peer and advocacy support

- Trauma-informed approaches to care

- Flexible care options that centre on provision of care at home

People with disabilities

People with disabilities often experience significantly poorer health than those without, and many are likely to require palliative care during their lives. However, challenges exist to ensuring access to quality palliative care that meets the needs of people with disabilities.

Key barriers and promising approaches for improving access to and experience of palliative care for people with disabilities include:

Barriers

- Lack of awareness/understanding of palliative care
- Communication issues (care providers and people with disabilities)
- Service provider assumptions about competence of people with disabilities
- Diagnostic 'overshadowing'
- Physical barriers (access, mobility, transport)
- Distrust of health services
- Inadequate support for carers and families
- Lack of integration between health, disability and aged care sectors
- In community living settings, lack of organisational support for dying in place of choice.

Promising approaches

- Community awareness-raising
- Education and training for palliative care, disability service staff and people with disability
- Support for carers and families
- Advocacy support
- Collaboration and inter-agency communication to boost capacity for community-based palliative care
- Development of organisational policies and processes to support delivery of palliative care.

People who are lesbian, gay, bisexual, transgender or intersex

People who are lesbian, gay, bisexual, transgender or intersex (LGBTI) face a number of barriers to accessing health care in general, and palliative care in particular. While many LGBTI people live happy and healthy lives, as a group they may be more likely than the general population to experience poor social, physical and mental health. LGBTI people also have a higher incidence of life-limiting illness, and tend to present to palliative care services with more advanced disease than the general population.

While often seen as a single group, 'LGBTI' includes several distinct, but sometimes overlapping, demographics each with their own distinct histories, experiences and health needs.

Key barriers and promising approaches for improving access to and experience of palliative care for this population group include:

Barriers

- Lack of awareness/understanding of palliative care

- Fear and experience of discrimination and bias, especially from faith-based services and in residential settings

- Heteronormative assumptions, including in publicity material, forms, and interpersonal communication

- Lack of recognition of LGBTI relationships and family of choice, including legal recognition

- Service providers' lack of knowledge, especially around trans and intersex health care

- Issues related to HIV/AIDS, including stigma, multiple morbidity, and neurodegenerative conditions

Promising approaches

- Awareness-raising, especially around community-based palliative care

- Strategies to identify inclusive services (e.g. Rainbow Tick certification)

- Visible signifiers of inclusion

- Language that avoids heteronormative assumptions

- Recognition and inclusion of partners and chosen family, including legal recognition

- Access to advocacy services

- LGBTI-specific education and training for care providers

People experiencing homelessness

People experiencing homelessness face multiple and complex challenges in life, and are more likely to have poorer health and die earlier compared to the general population. At the same time, the homeless population faces significant barriers to accessing services, including healthcare—and, by extension, palliative care.

Barriers and promising approaches for improving access to and experience of palliative care for this population group include:

Barriers

- Lack of awareness/understanding of palliative care

- Fundamental requirement to prioritise basic day-to-day needs

- Unstable or unsafe living environments

- Fear of being displaced from living environment

- Incompatibility of healthcare services with the realities of homelessness

- High prevalence of mental health and substance use issues

- Social and/or family isolation

- Feared, or actual, stigma and judgement

- Distrust of institutions and authority

- Lack of access to/use of primary care services, leading to crisis presentations

- Service providers' lack of knowledge, training and experience in providing care for people experiencing homelessness

- Difficulties in making accurate diagnoses and prognoses

Promising approaches

- Education and training in culturally-appropriate and trauma-informed approaches

- Recognition and consideration of the complex needs of the homeless population

- Collaboration between palliative care services and homeless support services

- Specialist homeless healthcare organisations

- Promoting and facilitating timely engagement between individuals and primary care services

- Flexible services and care environments (e.g. in-reach care in non-conventional care settings)

- Increasing integration and coordination across health and other services

- Adopting a harm reduction approach

- Appropriate funding, including, potentially, increased and protected funding.

People who are incarcerated

The Australian prison population is characterised by poor health and multiple disadvantage. The prison population is growing, and the proportion of older prisoners is increasing. These increases, combined with high rates of multi-morbidity, are likely to increase the need for palliative care services in this setting. However, palliative care can be challenging to deliver and access in this context.

Key barriers and promising approaches for improving access to, and experience of, palliative care for this population group include:

Barriers

- Lack of awareness and understanding of palliative care

- Attitudes of prison staff and tension between priorities of security and prisoner wellbeing

- Distrust of health services

- Lack of access to health services

- Challenging family relationships

- Physical and cultural environments of prisons are not conducive to provision of quality palliative care

- Lack of effective policies and processes for palliative care

Promising approaches

- Education and training for palliative care staff

- Development of palliative care-specific guidelines and pathways

- Collaboration and relationship-building between prisons and inpatient/community palliative care services

- Provision of alternative accommodation options for delivery of care

- Prison health literacy programs

Refugees

Refugees and asylum seekers often face a range of health and social challenges as a result of language and cultural issues, the disruption associated with their life experiences and adverse conditions in the community. They may have relatively poor health and complex needs requiring specialised, longer-term or more intensive services (including palliative care services), but these may be more difficult to access due to cost or eligibility issues.

Barriers and promising approaches for improving access to and experience of palliative care for this population group include:

Barriers

- Lack of awareness/understanding of palliative care

- Language and communication issues

  - Poor literacy/health literacy
  - Poor access to professional interpretation services

- Mismatching cultural, religious and/or health beliefs and preferences between refugees and service providers

- Difficulty accommodating cultural practices in palliative care settings

- Effects of trauma (including complex mental and physical health symptoms)

- Lack of/late referral to, or initiation of, palliative care

- Fear or distrust of services, reluctance to disclose information

- Social isolation and family separation

- Socioeconomic factors (lack of stable housing, financial resources)

- Eligibility issues (for publicly-funded care); legal, financial and/or duty-of-care considerations for those in detention settings

Promising approaches

- Community education and awareness-raising

- Cultural champions

- Culturally-appropriate and translated resources

- Access to appropriate professional interpreting services

- Training for professional interpreters (in palliative care concepts and terminology)

- Improved cultural competence within services

  - Education and training to increase understanding of the 'refugee experience'
  - Culturally-appropriate communication
  - Facilitating cultural elements and practices in service provision

- Taking time to build rapport with individuals, families and communities

- Access to telehealth (especially for those in rural and remote communities)

- Trauma-informed approaches to care

- Policy reform and development to support access to health care

Veterans

Veterans face unique circumstances in relation to accessing palliative care. While not all veterans have experienced active service, military involvement is associated with risk factors that can be detrimental to veterans' lives. In particular, historical trauma often creates a unique set of needs in this population, and many veterans experience significant health and social challenges.

While many have access to healthcare benefits through Department of Veterans' Affairs (DVA) entitlements, the scope and extent of available DVA health services and associated eligibility requirements mean that veterans still face challenges when accessing healthcare (including palliative care) that is *appropriately tailored* to their specific needs.

Barriers and promising approaches for improving access to and experience of palliative care for this population group include:

Barriers

- Veterans':
  - Lack of awareness/understanding of palliative care
  - Culture of independence and survival
  - History of trauma and associated issues (including mental health and social issues)
  - Lack of family support
- Service providers':
  - Lack of recognition, awareness and understanding of veterans' lived experience (especially the likelihood of history of trauma and its potential effects)
  - Lack of experience working with veterans
  - Gaps in education and training
- Challenges accessing and navigating DVA-administered and other benefits schemes

Promising approaches

- Community awareness-raising
- Acknowledgment and respect for veterans' lived experiences
- Trauma-informed approaches to care
- Appropriate information-gathering at start of care pathway (i.e. determining veteran status and service history)
- Expanded and/or simplified access to services funded under DVA benefit schemes

Appendix B. Project methods

Overview

The exploratory analysis of barriers to palliative care ran from February 2018 to June 2019. Project activities are described below.

Literature reviews

AHA conducted nine literature reviews focusing on the specified under-served populations. The purpose was to:

- Explore barriers and enablers to palliative care for each population group

- Explore barriers and enablers to advance care planning for each population group

- Inform the development of effective stakeholder engagement strategies for each group.

The initial search and review was undertaken in March and April 2018. The reviews were updated in January 2019.

The method, including the search strategy, inclusion/exclusion criteria and approach to analysis and reporting is described in the Literature Review.

Key informant interviews

Stakeholders with expertise and interest in barriers and enablers to palliative care were interviewed. These included service providers (including those in the palliative care sector, as well as other health and social care providers) peak body representatives, state/ territory government representatives, advocates and academics). Interviews took place between March 2018 and May 2019.

Stakeholder survey

The online survey was designed to gather the perspectives of organisational stakeholders (including staff, volunteers, academics and peak body representatives) on the under-served populations of interest. The survey included questions about barriers, enablers and promising strategies. Respondents were able to respond in relation to as many of the population groups as they wished, depending on their interest and experience. The survey was promoted widely to engage a broad range of stakeholders (including those within and outside the palliative care sector). Promotional strategies included:

- Notification request for key informants to promote the survey to their networks, via email, newsletters etc

- Direct email to approximately 350 organisations

- Promotion on AHA's social media channels.

The survey was open from 14 May to 14 June 2018.

Workshops

Organisational stakeholder workshops were held in each capital city in Australia between 6 September and 1 November 2018.

The overarching objectives of the half-day workshops were two-fold: to share findings from the project to date, as well as further explore the issues affecting access to palliative care for the identified populations. Specific aims were to explore:

- Promising approaches for supporting access to palliative care for the population groups

- The potential role of advance care planning

- Trauma-informed approaches to palliative care

- The roles of different stakeholder groups (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.

Two additional workshops were held via videoconference for those unable to attend in person.

Consumer/community consultations

AHA undertook focus groups or interviews (face-to-face or by phone) with individuals from the population groups of interest (excepting people who are incarcerated – see *Limitations* on p.69). Organisational stakeholders that participated in the key informant interviews and workshops assisted with recruitment for the consultations, by promoting them to their clients or networks. People did not need to have direct experience of palliative care to participate.

The purpose of the community consultations was to:

- Explore perceptions and understandings of palliative care (including who provides it, in what settings and under what circumstances)

- How people think and talk about end-of-life

- Possible reasons why people may not receive palliative care services, and how these could be remedied.

The Bellberry Human Research Ethics Committee reviewed and approved this component of the project in accordance with the National Statement on Ethical Conduct in Human Research (2007)—incorporating all updates.

Stakeholder engagement

High levels of stakeholder engagement were achieved throughout this project, as shown in

Figure B-1.

Input was received from all around Australia, as shown in *Figure B-2* and *Figure B-3*.

Many organisational stakeholders involved had an interest and expertise in palliative care generally, as providers, policy-makers, or academics. Others had a specific interest in one (or more) of the identified population groups, as highlighted in *Table B-1.*

Table B-1: Key informants and survey respondents by population groups of interest

Population group	Key informants (#)	Survey respondents (%)
Aboriginal and Torres Strait Islander peoples	11	66
People from CALD backgrounds	6	**72**
Care leaves and people affected by forced adoption	2	27
People with disabilities	8	67
People experiencing homelessness	5	41
People who are incarcerated	7	22
People who identify as LGBTI	5	52
Refugees	3	34
Veterans	4	43

A full list of organisational stakeholders consulted is provided on pp.72-73.

Figure B-1: Project activities

Literature review	Key informant consultations	Stakeholder survey	Workshops	Community consultations
> 390 sources	> 100 interviews	414 responses	170 attendees	184 participants

Analysis and reporting

Summary Policy Paper
9 Issues Reports
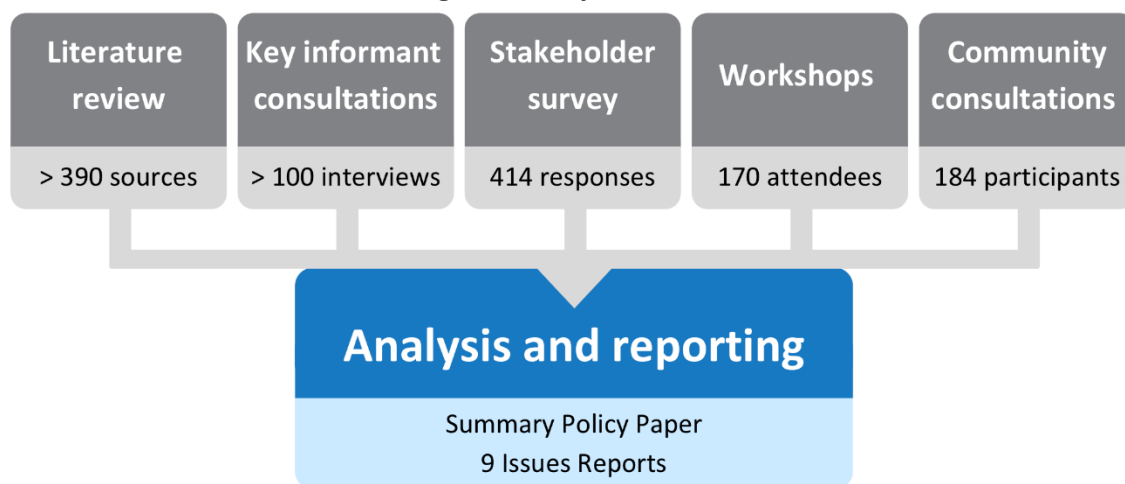
Figure B-2: Stakeholder workshops and community consultations

Community members

Aboriginal and Torres Strait Islander peoples: n =10
Care leavers and people affected by forced adoption: n = 36
People from culturally and linguistically diverse backgrounds: n = 71
People living with disabilities: n = 27
People experiencing homelessness: n = 4
People who are lesbian, gay, bisexual, transgender or intersex: n = 27
Refugees: n = 2
Veterans: n = 7

15 Workshop attendees

NT
Community members consulted:
n = 9

QLD
Community members consulted:
n = 10

29 Workshop attendees

NSW
Community members consulted:
n = 56

17 Workshop attendees

17 Workshop attendees

26 Workshop attendees

25 Workshop attendees

WA
Community members consulted:
n = 43

SA
Community members consulted:
n = 32

VIC
Community members consulted:
n = 13

28 Workshop attendees

TAS
Community members consulted:
n = 20

ACT
Community members consulted:
n = 1

13 Workshop attendees

Figure B-3: Geographical spread of stakeholder survey responses

Few responses — More responses
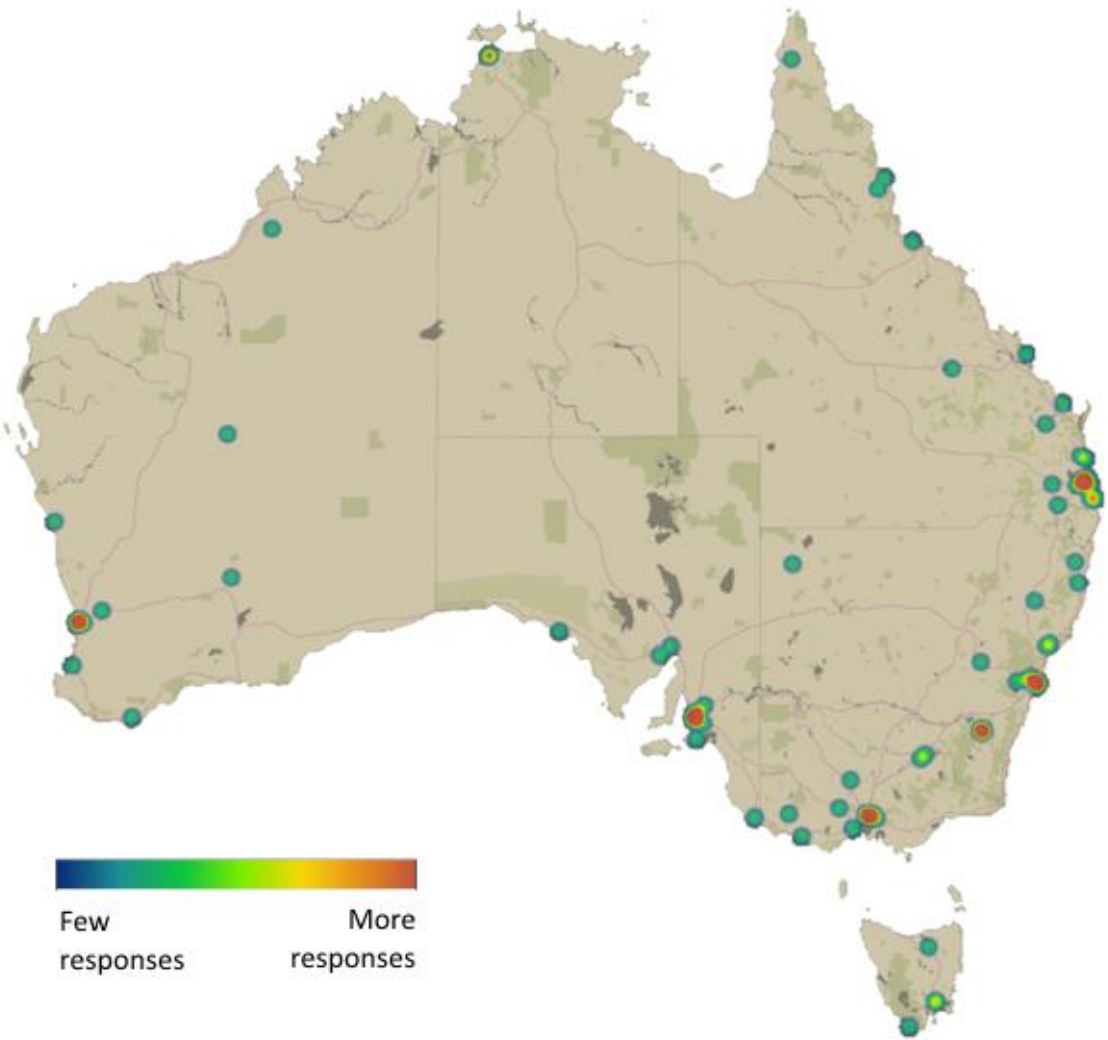
Limitations

While high levels of engagement were achieved for this analysis, there was a higher level of interest for some populations than others.

For organisational stakeholders:

Reasons provided by some organisational stakeholders for not contributing to the project included:

- A view that palliative care was not (or only indirectly) related to their work—particularly among those whose roles sit outside of the health sector. These stakeholders felt that they did not have relevant insights to contribute

- Time and resource constraints—particularly for those in client-facing roles (in the health sector and other services).

For community members/consumers:

Organisational stakeholders (who assisted with recruiting community members for focus groups and interviews) reported that some individuals were reluctant to participate. Reasons mirrored the barriers to accessing palliative care described in the issues reports. These may have included:

- A perceived lack of insight into palliative care (and therefore a sense that they would have little to contribute)

- An unwillingness to talk about dying and death

- More pressing concerns relating to personal circumstances (e.g. for people experiencing homelessness)

- A distrust of speaking with strangers or agencies perceived as connected with government.

As a result of these limitations, it is likely that the consumers who participated in the consultations:

- Had a greater awareness of, or more experience with, palliative care

- Were more confident to talk about dying and death

- Experience fewer or less challenging barriers in terms of accessing services in general.

It was not possible to consult directly with people in prison.

Many community members participating in consultations belonged to more than one of the identified under-served population groups. As they were not asked to disclose which additional group(s) they belonged to, they have been categorised based on the service/organisation through which they were recruited.

These factors, along with the acknowledged diversity of the population groups, mean that the views of those participating in consultations should not be considered representative of the broader population.

A small number of case studies are included in the issues reports arising from the project. These are intended to highlight examples of approaches that engage or provide appropriate palliative care services for members of under-served population groups. They do not result from a comprehensive review of all services and initiatives, and therefore represent 'promising' rather than 'best practice' approaches.

Stakeholders consulted

National

- Advance Care Planning Australia
- Catholic Health Australia (CHA)
- Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM)
- CRANAplus
- Dementia Australia
- Department of Veterans' Affairs (DVA)
- Federation of Ethnic Communities' Councils of Australia (FECCA)
- Alliance for Forgotten Australians
- LGBTI Health Alliance
- Melbourne Legacy
- National Aboriginal and Torres Strait Islander Health Worker Association (NATSIHWA)
- Palliative Care Australia
- Palliative Care Interest Group
- Program of Experience in the Palliative Approach (PEPA), National Indigenous Program
- Purple House
- Settlement Council of Australia

Australian Capital Territory (ACT)

- Palliative Care ACT
- Canberra Hospital Palliative Care Clinical Network
- Justice Health Services ACT
- The Centenary Hospital for Women and Children ACT

New South Wales (NSW)

- Palliative Care NSW
- Western Sydney University
- The University of Sydney: Centre for disability research and policy
- The University of Sydney: Sydney Pharmacy School
- Northern Territory (NT)
- Department of Health
- Palliative Care NT
- Royal Darwin Hospital

Queensland (Qld)

- BlueCare
- Corrections Qld
- Darling Downs Health (Goondiwindi Hospital)
- Department of Health Qld
- Mater Cancer Centre
- Metro South Palliative Care
- Palliative Care Qld
- PEPA Qld
- Salisbury Medical Group

South Australia (SA)

- Flinders University
- Helping Hand
- Hutt St Centre
- Independent consultant
- Independent researcher
- Northern Adelaide Palliative Service and The University of Adelaide
- SA Prison Health Service

- Sonder (formerly Northern Health Network)
- Southern Adelaide Palliative Services
- Palliative Care SA

Tasmania (Tas)

- Correctional Primary Health Services Tasmania (CPHS)
- Department of Health Tas
- Bereavement Care Network Tasmania
- Li-Ve Tasmania
- Palliative Care Tas
- The District Nurses

Victoria (Vic)

- Aged and Health Support Unit at Returned and Services League (RSL) VIC Head Quarters
- Barwon Health
- Bolton Clarke
- Department of Health Vic
- Disability Advocate
- Groundswell
- Justice Health
- La Trobe University
- La Trobe University, Healthy End-of-Life Project (HELP)
- Melbourne City Mission
- Monash University
- Palliative Care Vic
- St Vincent's Hospital, Melbourne
- Thorne Harbour Country
- Thorne Harbour Health
- Victorian Refugee Health Network

- Warrnambool and District Community Hospice
- Warrnambool RSL
- Wintringham Specialist Aged Care

Western Australia (WA)

- Aboriginal Health Council of WA (AHCWA)
- Bethesda Health Care Metropolitan Palliative Care Consultancy Service (MPaCCS)
- Department of Health WA
- GLBTI Rights in Ageing Inc (GRAI)
- Homeless Healthcare
- Kalgoorlie Hospital
- Midwest Palliative Care, Northern and Remote Country Health Service
- North Metropolitan Health Service and WA Cancer & Palliative Care Network
- North Regional TAFE
- Palliative Care Service, WA Country Health Service Great Southern
- Palliative Care WA
- WA Country Health Service—Kimberley

Other

AHA also acknowledges the contribution of our external advisors who reviewed materials and provided valuable input throughout the project:

- Dr Jane Fyfield
- Prof Margaret O'Connor
- Ms Katrina Récoché.