



Australian Government Department of Health

Exploratory Analysis of Barriers to Palliative Care

Issues Report on Aboriginal and
Torres Strait Islander Peoples

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

Acknowledgments

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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.¹ 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,

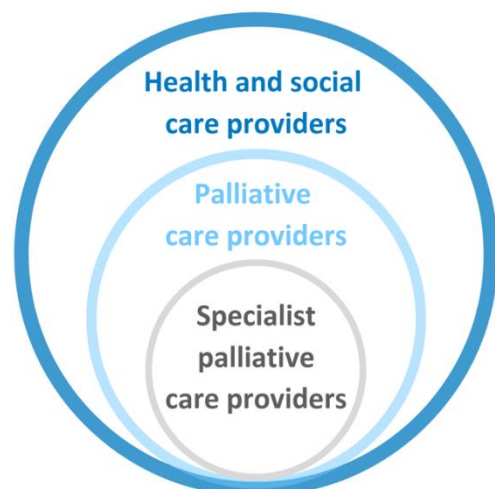
including volunteers, depending on the patient's needs. These may include:

- 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.



Key messages

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 Australian 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

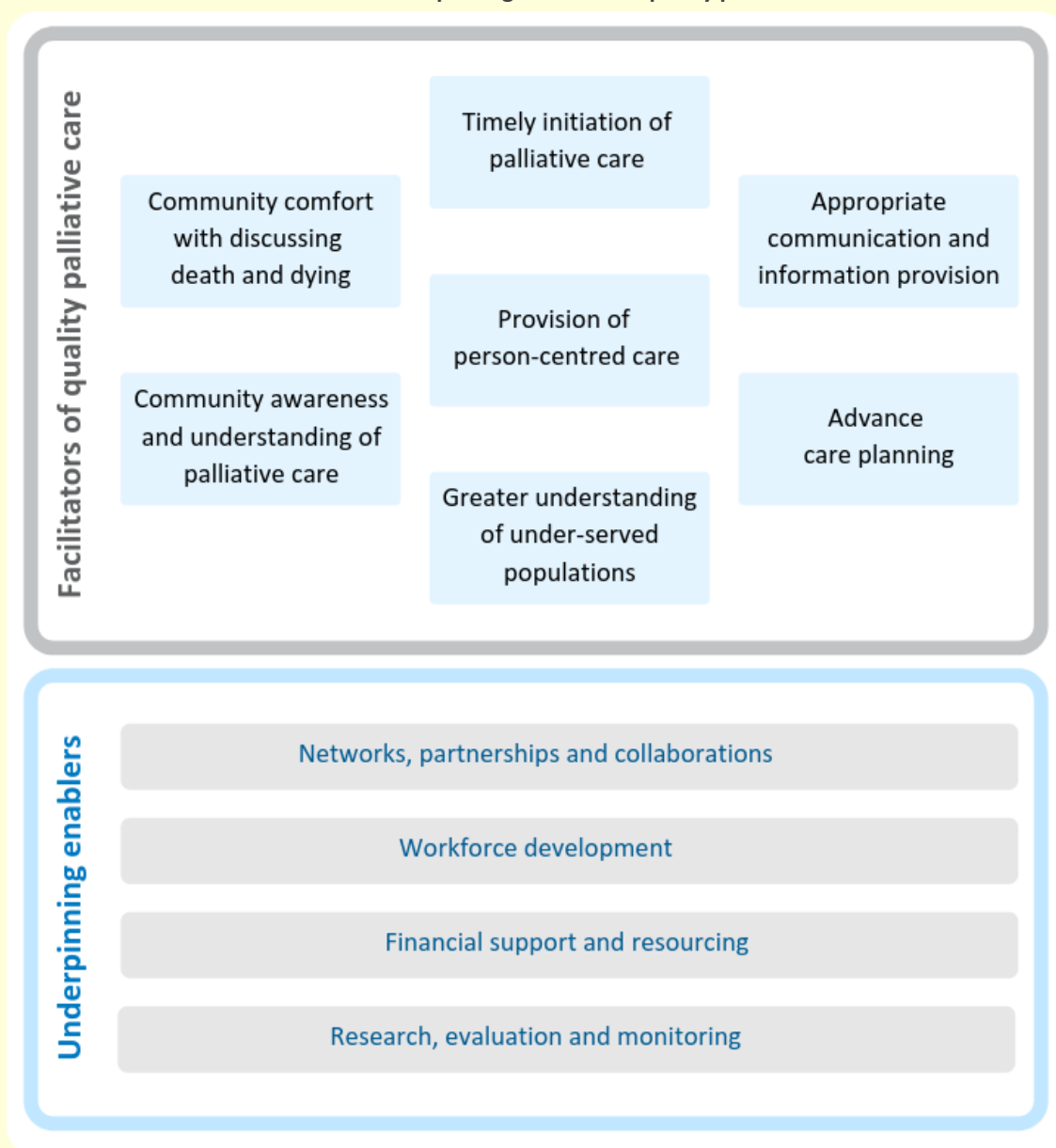
- Community awareness-raising
- Engagement between services and communities
- Recruitment of Aboriginal and Torres Strait Islander staff
- Culturally-appropriate and translated resources
- Culturally-appropriate engagement with individuals and families
- Access to appropriate professional interpreting 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
- Patient navigator initiatives

Recommendations

Recommendations address seven domains that facilitate quality palliative care. These are underpinned by four key enablers, as illustrated below.

Specific recommendations are detailed in *section 4*.

Facilitators and underpinning enablers of quality palliative care



1 | Project background

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

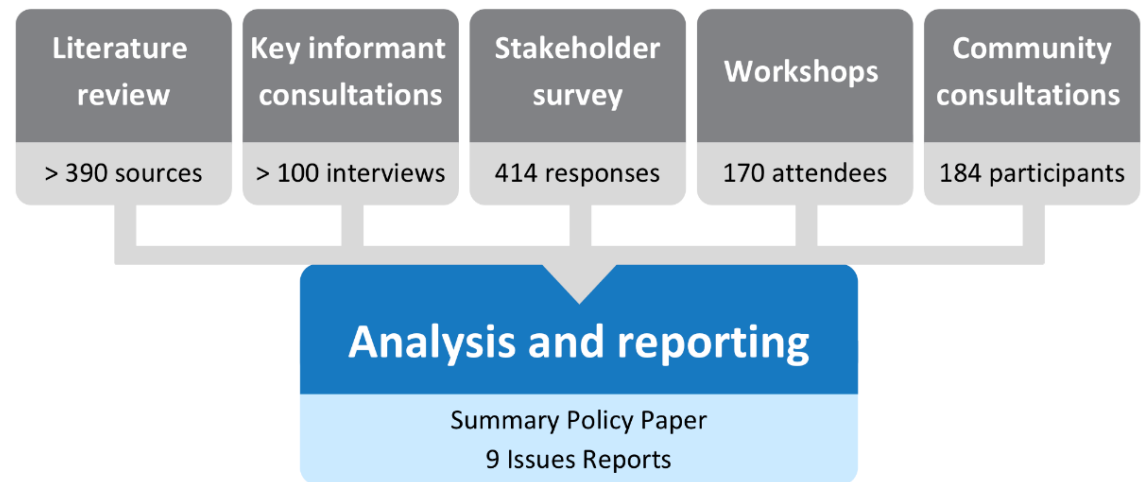
The project generated a high level of engagement from a broad range of stakeholders.

AHA acknowledges that the community members consulted for this project may not be representative of the broader Aboriginal and Torres Strait Islander community.

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'.

Please refer to the *Summary Policy Paper* for more information on project methodology and limitations.

Figure 1-1: Project activities



This report

This issues report describes key barriers and promising approaches for improving Aboriginal and Torres Strait Islander peoples' access to and experience of palliative care in Australia. It also discusses the potential role of advance care planning and provides recommendations for the palliative care and

other sectors to improve access and quality of care for Aboriginal and Torres Strait Islander peoples.

This issues report is part of a suite of documents developed through the project, as shown in *Figure 1-2*.

Figure 1-2: Suite of reports



2 | About this population group

Aboriginal and Torres Strait Islander peoples are defined by descent (i.e. a parent is of Aboriginal or Torres Strait Islander descent), self-identification (i.e. the individual identifies as Aboriginal and/or Torres Strait Islander) and community recognition (i.e. the individual is accepted as Aboriginal or Torres Strait Islander by the community in which they live).²

Aboriginal and Torres Strait Islander peoples currently represent 3.3% of the Australian population (almost 800,000 individuals), with this proportion increasing over time.³

Context

The Australian Government considers Aboriginal and Torres Strait Islander peoples over the age of 50 'aged', compared with 75 years and older for the non-Indigenous community, reflecting the considerable discrepancies in health and life expectancy.⁴ The mortality rate among Aboriginal and Torres Strait Islander peoples is 1.6 times that of non-Indigenous Australians, with cardiovascular disease and cancer the leading causes of death.⁵ While cancer diagnosis rates are overall lower than for the general population, Aboriginal and Torres Strait Islander peoples are less likely to participate in cancer screening, are less likely to receive adequate treatment for cancer, and have a higher age-standardised mortality rate from cancer (which is also increasing).⁶

Given the gap in mortality rates, Aboriginal and Torres Strait Islander peoples experience the death of family, friends and community members far more frequently than the non-Indigenous population, and for some communities, death is so frequent that they 'are in either acute or chronic shock from constant bereavement'.⁷ These and other experiences of trauma and loss have intergenerational effects.⁸

There is a need to understand that all Aboriginal and Torres Strait Islander communities in Australia have a common heritage of loss, and that for an individual close to death and for their family and community, the impact of the loss and grief is often compounded by earlier experiences⁹

In a broader sense and through complex mechanisms, Aboriginal and Torres Strait Islander communities' history of dispossession, racism and systemic discrimination has contributed to barriers to healthcare access and significant health disparities.¹⁰ Between the late 1800s and 1970s, many Aboriginal and Torres Strait Islander children were forcibly removed from their families—so many that *'almost every Aboriginal family today can identify one or more family members lost'* as part of the **Stolen Generations**.¹¹ These factors may be of particular importance in the context of palliative and end-of-life care for Aboriginal and Torres Strait Islander peoples. Issues relating to people from Stolen Generations are also discussed in the *Issues Report on Care leavers and people affected by forced adoption*.

The rate of palliative care-related hospitalisations across public hospitals in Australia is about twice as high for Aboriginal and Torres Strait Islander peoples as for other Australians.¹² Conversely, in 2015-16, only 1.3% of palliative care-related encounters in general practice were recorded as being provided to Aboriginal and Torres Strait Islander peoples. Given that Aboriginal and Torres Strait Islander peoples comprise 3.3% of the Australian population, this suggests that these populations are under-represented in general practice-based palliative care.¹³

3 | Findings

During the project it was noted that many of the issues identified as barriers, enablers and promising approaches to accessing palliative care by Aboriginal and Torres Strait Islander peoples were actually *universal factors*, i.e. common to the general Australian population, rather than being specific to Aboriginal and Torres Strait Islander peoples. These universal factors, along with a range of other factors that are common to all under-served populations, are described in the *Summary Policy Paper* from this project. The discussion below focuses on factors identified as *specific to Aboriginal and Torres Strait Islander peoples*.

Many of the barriers raised through consultations and described below apply to health care and aged care more broadly and are not specific to palliative care.

It is also recognised that Aboriginal and Torres Strait Islander peoples and communities are heterogeneous, and, while findings and recommendations in this issues report are generalised, they are unlikely to be relevant in all cases.

‘You need to be culturally responsive to the local Aboriginal and Torres Strait Islander population—they’re not homogeneous’

—Stakeholder workshop participant

‘Most Aboriginal and Torres Strait Islander material is focused on Aboriginal people. Torres Strait Islanders cannot connect so well with it’ —Government representative

The barriers and enablers identified in this report have been categorised as ‘consumer-side’ and ‘service-side’. Consumer-side factors relate to characteristics of individuals, families and communities, while service-side factors relate to health professionals, services and organisations, and the healthcare system more broadly. These categories are not intended to lay fault for barriers or responsibility for enablers on one particular side of the palliative care relationship, but rather to provide a framework within which to consider an appropriate service system response.

‘What it means to be Aboriginal is a conversation that has to be had with the individual’
—Aboriginal cultural consultant

Barriers to accessing palliative care

Consumer-side barriers

As with all under-served populations—and the general population—a **lack of awareness and understanding** of palliative care may be a common barrier to access for Aboriginal and Torres Strait Islander peoples, including what it is, how it could help, which professionals are involved and what services are available.

Aboriginal and Torres Strait Islander peoples may also have significant **fear or mistrust of ‘Western’ medicine and/or healthcare providers and services**. In some cases this may be due to personal experiences of illness, death and grief, or other negative experiences including perceived and experienced discrimination within healthcare (and other) settings. It may also relate to transgenerational trauma, grief and loss, as mentioned on p.5.

In many instances, **language and communication barriers** are major issues in facilitating access to palliative care services, and in receiving the most appropriate care. While English is the main language spoken by the majority of Aboriginal and Torres Strait Islander peoples, more than 150 Indigenous languages are spoken by tens of thousands of Aboriginal and Torres Strait Islander peoples in their homes, and English proficiency varies. Aboriginal and Torres Strait Islander peoples living in rural and remote areas are more likely to not speak English well, or at all.¹⁴

‘Lots of Aboriginal and Torres Strait Islander people have English as a second or third language. There will be ongoing barriers until we acknowledge that’ —Peak body representative

In addition, communication difficulties can result from different understandings of health and disease, and in some cases a lack of direct translation for relevant terms and concepts. While customs and beliefs vary, some Aboriginal and Torres Strait Islander individuals and communities may consider talking about death and dying to be **taboo, or ‘bad talk’**, making it difficult to initiate conversations about palliative care. Even where this is not the case, talk about death and dying may not include the concept of palliative care.

*‘Talk on the ground is that if you talk about [dying], it will happen’
—Palliative care education provider*

*‘Talking about death is taboo for Aboriginal people. So once end-of-life plans get discussed in clinic, people may stop showing up’
—Peak body representative*

*‘There is talk about death and dying but not “palliative care”’
—Palliative care education provider*

'It's very difficult to talk about or be around people who are dying. I've seen that much death'

—Aboriginal community member

'We work closely with [Indigenous Health Workers] but, culturally, the inability to talk about these things...it's a real barrier'

—Palliative medicine physician

Aboriginal and Torres Strait Islander cultural understandings may also be incongruent with Western biomedical explanations regarding the development, progression and treatment of disease. Some individuals may hold aspects of both traditional Aboriginal and Torres Strait Islander and Western belief systems simultaneously.

'[Aboriginal and Torres Strait Islander] people walk in two worlds'

—Service provider

Aboriginal and Torres Strait Islander peoples may not believe that non-Indigenous health professionals understand the importance of their cultural or spiritual beliefs in end-of-life care, and may therefore be reluctant to talk about these issues. **'Cultural shyness'** may also mean that Aboriginal and Torres Strait Islander patients do not speak openly and/or assertively with care providers about their needs and preferences.

These differences, and potential mistrust of mainstream services, may mean that Aboriginal and Torres Strait Islander people are less likely to present to medical services until in advanced stages of illness, when end-of-life becomes a crisis situation. In addition, with high rates of chronic disease among Aboriginal and Torres Strait Islander peoples, sickness may be normalised,

meaning there is little planning for palliative care and end of life.

'Everyone's got sugar [diabetes]—so what?' —Aboriginal community member

Kinship and the extended family network may hold increased importance for Aboriginal and Torres Strait Islander peoples relative to a Western model of palliative care.¹⁵ Caring for unwell and dying family members is considered by many an important family responsibility.¹⁶ Aboriginal families' care for dying family members might include the preparation of bush food, as well as music and singing.¹⁷ Traditionally, **kinship rules may determine who is the right person to provide care**,¹⁷ and care by a person of the opposite sex may bring shame or embarrassment.¹⁸

'The hospital expects one "family meeting" and an immediate decision, but that is not possible, because the family members who are in the meeting need to speak to others who are not in the meeting, and it can take a while to find all the family members'

—Service provider

For many Aboriginal and Torres Strait Islander peoples, there is a strong desire—if not a cultural imperative—to **die on country**.

However, there can be great (and sometimes insurmountable) logistical challenges in adequately supporting this, and numerous barriers not just for service providers (discussed below), but also individuals and family members.

‘Being Aboriginal, we want to stay where we are for as long as we can. We need support to do that, either from family or others’
—Aboriginal community member

In different contexts, a desire to die on country may mean:

- Refusing to travel for treatment (e.g. dialysis)
- Not travelling to access palliative care services (where not available or sufficient locally)
- Wishing to travel to return ‘home’ (either current or traditional), if not already there.

‘Aboriginal people are very reluctant to go into town because they prefer to die on country. They realise they could be flown into town, never to return’

—Service provider

‘If a person wants to go home, but there’s a lack of access to palliative care services and specialist equipment, that person has little choice’ —Peak body representative

Family members may not have any (or adequate) support to provide care (e.g. bathing, toileting) for a loved one at home. In some cases, housing may be overcrowded, meaning that there is no private space for providing care. Family members may be unwilling to administer medicines for fear of poisoning (and associated blame within the community) or because interfering with suffering might be considered inappropriate for a culturally-determined sickness.

‘Sometimes there is blame for letting the dying person become so ill, or for allowing them to come home when so unwell. It’s distressing for everyone’
—Aboriginal community member

Other practical difficulties with dying on country may arise. For example, in some Aboriginal cultures, once a person has died in a house, that place must be abandoned for a period of time.

Being displaced from community in order to access palliative care services can be traumatic for individuals and their families, bringing feelings of isolation from country and community, homesickness and sadness. It may also prevent an individual from completing cultural obligations within their community.

‘They know the stories, they know how to look after their country; they have an obligation to pass on knowledge’
—Service provider

Financial disadvantage, along with **costs** associated with palliative care, was also mentioned as a significant barrier both in the literature and by stakeholders. This was often coupled with reluctance or shame associated with ‘asking for a handout’.

Service-side barriers

Health professionals

As for most under-served population groups, a **lack of or late referrals** was reported to hamper Aboriginal and Torres Strait Islander people’s access to specialist palliative care services. More broadly, and as for all under-served populations, there may be a lack of early recognition of palliative care need and initiation.

‘We just aren’t getting the referrals’
—Service provider

‘There is a lack of appropriate referrals along the trajectory’
—Stakeholder workshop participant

Language and communication barriers—discussed in detail above—are relevant on the service side as well as consumer side. In some cases, health professionals may not feel comfortable raising the topic of death and dying with Aboriginal and Torres Strait Islander peoples.

As with other culturally and linguistically diverse groups, a **lack of cultural competence** on the part of care providers and services is a key barrier to accessing palliative care for Aboriginal and Torres Strait Islander peoples. Non-Indigenous service providers may:

- Not have training or experience in working with Aboriginal and Torres Strait Islander peoples in the palliative care setting

- Lack education, awareness, acknowledgment and respect for cultural diversity, safety and sensitivity
- Have limited understanding of individuals’ cultural obligations and how these obligations may affect their willingness and ability to receive palliative care
- Lack understanding of the family unit and relationship dynamics
- Display discriminatory or racist attitudes and behaviours
- Lack empathy or understanding of transgenerational trauma.

Racism and discrimination by health professionals can clearly present barriers to timely and effective palliative care, as can a lack of acknowledgment and empathy for transgenerational trauma. **Cultural stereotypes** can also hamper access. In some cases, institutional racism was reported by stakeholders as a key issue affecting Aboriginal and Torres Strait Islander peoples in palliative care, and broader healthcare contexts.

‘GPs may perceive that Aboriginal people don’t want to talk about dying, so they make a choice based on assumptions, rather than what the patient may actually want’
—Peak body representative

‘[There is] ongoing systematic treatment of [Aboriginal and Torres Strait Islander] individuals as ‘second-class citizens’ —Stakeholder survey respondent

Services or organisations

In remote areas, specialist palliative care services may be minimal or non-existent. Even in urban areas, **culturally-appropriate services and care environments may not exist** for Aboriginal and Torres Strait Islander peoples. For example, services may not be able or willing to accommodate the presence of large numbers of family members, specific mourning and grieving customs, access to traditional healing practices, or cultural ceremonies to assist the spirit to leave the physical body. Kinship arrangements and family involvement in decision-making may also not fit a service provider’s model.

*‘Katherine has a very small palliative care unit—just one room in the hospital. It is too small to have more than one family member stay in, but often six to eight kin would wish to be with the dying person’
—Aboriginal community member*

‘Trying to coordinate services [in remote areas] is hard. Even though we do telehealth, we rely on the clinics a lot because they know the patients better, and then we may need to organise with the community health centre to meet the family with us, too’ —Service provider

Stakeholders reported **limited availability, as well as use, of accredited interpreters** for Australian Indigenous languages within health service delivery. In circumstances where interpreters are available, they may have little or no understanding of palliative care.

*‘It’s difficult in rural areas due to a lack of trained interpreters in palliative care, and because it’s taboo to talk about death and dying. We have had to recruit our own interpreters to do this work, and try to break through the barriers’ —
Service provider*

‘We have interpreters in the busy hospitals, but once they come into the hospice, the family typically takes over more of that role’ —Service provider

A lack of Aboriginal and Torres Strait Islander peoples in the workforce

in relevant sectors (including palliative care and health care more broadly) also maintains—if not creates—barriers to palliative care. While Aboriginal Health Workers (AHWs) and Aboriginal Liaison Officers (ALOs) are theoretically in an ideal position to ‘bridge the gap’, they may feel torn by cultural and professional obligations, and fear blame for involvement in a person’s death. In hospitals, they may be isolated from other staff, or not have good relationships with the palliative care team. Community relationships may be of benefit in this role, but may also raise challenges.

‘It would be nice to have more Indigenous Health Workers trained up to bridge the gap between mainstream services and Aboriginal and Torres Strait Islander service users’ — Palliative care education provider

*‘[Aboriginal Health Workers] will often understand the family dynamics and may be related, which can make it easier for families. But this can also have a big impact on these workers; they need to be able to debrief afterwards. There’s not much formal support for them’
—Peak body representative*

*‘We have an Aboriginal Liaison team in the hospital, but often the person translating is actually related to the patient, and that’s a problem’
—Peak body representative*

‘There may be cultural issues between the Aboriginal Health Worker and the client’ —Stakeholder workshop participant

‘ALOs are crucial to health services, but there is enormous pressure put on them’ —Stakeholder workshop participant

While better support for people to die on country is desirable, many practical barriers exist, including issues relating to the local workforce (e.g. lack of skill and confidence in providing palliative care), equipment, facilities, transport, telephone service, access to medicines, carer supports and access to specialised care.

‘The palliative care team doesn’t have a budget for travel to help people get home’ —Service provider

‘It’s a huge challenge trying to supply and then retrieve equipment in remote areas’ —Peak body representative

*‘Clinics on community do not have morgues. Freezers—when available—are always full, and often the body has to be flown out to a larger community town while funeral arrangements are made, which could take months’
—AHW education provider*

Enablers and promising approaches

Consumer-side enablers

Building awareness of palliative care and services available within communities, and developing trust and long-term relationships are key to promoting access to and uptake of palliative care. Strategies might include:

- Community education
- Long-term engagement between services and community elders and emerging leaders.

Capacity-building within communities may also strengthen Aboriginal and Torres Strait Islander people's ability to care for family and community members in their preferred settings (e.g. home, community).

Service-side enablers

Strategies for enabling access to palliative care for Aboriginal and Torres Strait Islander peoples include **culturally-appropriate engagement with families** at the point of palliative care need and, more broadly, supporting **community capacity-building**.

'We aim to minimise risk but the most important part is talking to families, so when [people] do die on country there's no one blamed and it's a good thing' —Service provider

'Working with Aboriginal and Torres Strait Islander communities needs ongoing work because it's relational, there needs to be trust'
—Palliative medicine physician

However, while '**culturally-appropriate care**' is often suggested in the context of care for Aboriginal and Torres Strait Islander peoples, 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'.¹⁹ Person-centred care for Aboriginal and Torres Strait Islander peoples should be culturally appropriate, but exactly what this means will vary between communities and individuals.

'The culture is changing and there is nothing you can't sit down and talk to people about, so everyone comes to an understanding and the patient can say what they want'
—Service provider

Despite this, **cultural competence and safety** within services is a key enabler of access to palliative care for Aboriginal and Torres Strait Islander peoples. Building such competence requires a multifaceted strategy, including **workforce development** activities such as:

- Employing Aboriginal and Torres Strait Islander peoples in all relevant roles (nurses, doctors, liaison officers, health workers, education and management), and training them in palliative care concepts
- Education and training for staff across relevant sectors, including:
 - Education of the palliative care (and broader health and social care) workforce to improve cultural competence

- Education of Aboriginal and Torres Strait Islander health care and support workers in palliative care (e.g. through the Program of Experience in the Palliative Approach (PEPA)).

Although not currently widely applied within palliative care services, **trauma-informed approaches** may be appropriate in providing palliative care for Aboriginal and Torres Strait Islander peoples, acknowledging not only personal experience where relevant but also transgenerational trauma that affects many in Aboriginal and Torres Strait Islander communities.

*‘A trauma-informed lens would benefit Aboriginal and Torres Strait Islander people—and all clients—in the context of palliative care’
—Stakeholder workshop participant*

*‘We are creating and redesigning the content and training in our workshops to embed trauma-informed care—there is a need to acknowledge the transgenerational trauma that has come through’
—AHW education provider*

Greater flexibility within services, including an ability and willingness to adapt ‘conventional’ processes to support cultural needs, was recognised as a key enabler of

appropriate palliative care for Aboriginal and Torres Strait Islander peoples. For ‘mainstream’ services, this may include, for example, more appropriate accommodation (e.g. to cater for larger family groups, furnished/decorated in a culturally sensitive manner), relevant support for families, and openness to facilitating cultural requests relevant to end of life (e.g. smoking ceremonies).

*‘For example, I have been meeting Aboriginal leaders about engaging a traditional Ngangkari healer to offer services’
—Service provider*

‘Sometimes when an Aboriginal person dies at home, the family has to abandon the house for a certain amount of time. It could be years. Now, if palliative care staff collaborated with the family to discuss their preference with respect to death practice and rituals for the patient, it may be acceptable for the patient to die in the clinic’ —Service provider

*‘My people like to get back to Mutton Bird Island. One person I know ended up staying four weeks. They brought in a generator for her. I’ve heard of people being transported by helicopter to get back to the islands’
—Aboriginal community member*

Partnerships and networks are also key. These include organisational relationships, referral pathways and collaborative service provision (e.g. between palliative care services and Aboriginal Health Services). These relationships have the potential to increase the capacity of Aboriginal Health Services to provide palliative care in the most appropriate setting and manner. A broad range of partnerships and networks currently exist and are being developed to assist early, proactive identification of palliative care needs and to strengthen community capacity to deliver and access palliative care, based on local needs and resources. Networks might comprise palliative care services, other healthcare providers, Aboriginal community-controlled organisations, education providers, aged care providers and peak bodies.

On the practical side, **building capacity within communities** (particularly in rural and remote settings) to provide palliative care locally can enable culturally-appropriate (and person-centred) care. Along with the partnerships and networks described above, key enablers may include:

- More palliative care beds in rural and remote areas
- Outreach services
- Equipment loan schemes
- After-hours service options
- Telehealth approaches.

In some cases, **Aboriginal and Torres Strait Islander patient navigators** have been used to assist Aboriginal and Torres Strait Islander peoples in navigating health care—including palliative care.

‘A good story is the Aboriginal Cancer Care Coordinators—their rapport with clients, families and the treating doctors has proven critical in getting clients referred to palliative care in a timely manner’
—Service provider

The Purple House

The Purple House is a not-for-profit, Aboriginal-run organisation based in Alice Springs, NT, that supports remote Aboriginal people with end-stage kidney disease. The Purple House has grown significantly over the past 16 years and now has 15 staff, 16 remote dialysis units in remote NT and WA, and the Purple Truck—a mobile two-chair dialysis unit. The Purple House was established because of the challenges faced by people who had to travel away from country to Alice Springs for dialysis, which caused ‘fundamental feelings of homesickness and sadness’.

Given the life-limiting nature of end-stage kidney disease, provision of palliative care is an integral part of the Purple House’s work, and the key goal is to get people back to country. The Purple House does this by talking to patients and families to understand their wishes and concerns about their care—by asking ‘what would it take for you to feel alright about this?’ Cultural priorities are front and centre, and the model of care is underpinned by ‘deep caring and deep listening’.

With input and advice from specialist palliative care services, the Purple House supplies whatever is identified as lacking. This might be basic equipment (bed bases, mattresses, blankets, wheelchairs) and/or extra workers/carers to support family with the task of helping someone to die on country. There is a cultural imperative to look after one’s

community—‘holding on close to people’—and by supporting people to fulfil this mutual obligation, the Purple House helps to build a sense of agency within communities.

‘In Central Australia they say the spirit is held in the kidney. This project is about keeping the spirit alive and strong: being on country, being with family, taking part in ceremony. And compassion’

The Purple House is achieving impressive outcomes in supporting people to have a ‘good life and ultimately a good death’. However, it would like to see more funding available to transport patients back to country (they currently rely on the Royal Flying Doctor Service waitlist or private charters), and improved access to equipment and medications. In addition, earlier involvement of physician palliative care services would be beneficial—due to resource constraints, it is currently difficult to access palliative care input while a patient is on dialysis, because it is considered ‘active treatment’.

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.²⁰

Advance care planning does not currently appear to be common within Aboriginal and Torres Strait Islander populations.

Many of the barriers to talking about palliative care noted above also apply to advance care planning, including cultural taboos or unwillingness to talk about death or dying.

Advance care planning can be an empowering process, but only if done in a culturally-appropriate and sensitive way that recognises the diversity of languages, terminology and preferences. Of particular note is the suggestion that early discussion of end-of-life preferences 'could play an important part in preventing unnecessary displacement of patients by allowing those who wish to die in their community to do so'.²¹ Conversely, however, it may be less useful in cases where services that may be desired are not available locally.

'There's no point having an advance care plan if there are no services available in your community'
—Stakeholder workshop participant

The best health provider to raise these issues with an Aboriginal and Torres Strait Islander person is likely to vary from case to case (e.g. palliative care nurse, AHW), as will the most appropriate family and community members to involve. Advance care planning may be better addressed by a person's usual care team rather than a palliative care service, but training may be required to support health and social care providers who are asked to fulfil this role.

'Advance care planning needs to be integrated into chronic disease care planning'
—Stakeholder workshop participant

'It is more appropriate and safer to address [advance care planning] with the healthcare services people know'
—Stakeholder workshop participant

In many cases, less formal advance care planning—rather than completion of ACDs—may be more acceptable and relevant to Aboriginal and Torres Strait Islander peoples.

Improving uptake of advance care planning within Aboriginal and Torres Strait Islander communities is likely to require education, awareness-raising and the efforts of local 'champions'. A number of resources have been developed to support Aboriginal and Torres Strait Islander peoples through advance care planning processes (see next page), but a co-design and whole-of community approach to promoting and supporting the concept may be required within local contexts.

Advance care planning resources for Aboriginal and Torres Strait Islander peoples

A number of resources have been developed for service providers and community members to support advance care planning within Aboriginal and Torres Strait Islander communities. These include:

- [Caring for your mob at the end of their life](https://www.health.gov.au/sites/default/files/caring-for-your-mob-at-the-end-of-their-life.pdf)ⁱ
- [Dying to talk Aboriginal and Torres Strait Islander discussion starter](https://dyingtotalk.org.au/aboriginal-torres-strait-islander-discussion-starter/)ⁱⁱ
- [Respecting Patient Choices \(Austin Health\) Advance Care Planning with Aboriginals and Torres Strait Islanders](https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/aboriginal_torres_strait_islander_advance_care_planning.pdf?sfvrsn=2)ⁱⁱⁱ
- [Advance Care Yarning](https://www.swslhd.health.nsw.gov.au/Carers/content/pdf/Advance_care_yarning.pdf)^{iv}
- [Advance Care Planning Australia's Taking control of your health journey](https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/taking-control-of-your-health-journey.pdf)^v
- [Aboriginal and Torres Strait Islander palliative care social comic: Pop Arthur](https://pepaeducation.com/pepa-mentors/indigenous-palliative-care-social-comic/)^{vi}.

An advance care yarning app has been developed in Goondiwindi, Queensland to assist Aboriginal and Torres Strait Islander community members when it comes to understanding, discussing and making choices about their care.

The app was co-designed with an Indigenous reference group, cultural unit staff and other community members. It is easy to understand, with culture- and language-specific content and a design that reflects Aboriginal and Torres Strait Islander spiritual

needs. It provides individuals and families with opportunities to talk through what is important to them in the context of palliative care, improves access to culturally-appropriate information and helps guide Aboriginal and Torres Strait Islander peoples in making choices about their family, wishes and healthcare.

The app is currently used by an Indigenous Health Worker to facilitate and document conversations about a patient's needs and preferences. It may require a number of visits to complete a 'summary of choices' that can be printed off, signed by a medical officer and retained on file.

'This technology provides opportunities for Aboriginal and Torres Strait Islander people to document their wishes, ensuring they have a voice and that health professionals, family and community members know how they want to be cared for'

ⁱ <https://www.health.gov.au/sites/default/files/caring-for-your-mob-at-the-end-of-their-life.pdf>

ⁱⁱ <https://dyingtotalk.org.au/aboriginal-torres-strait-islander-discussion-starter/>

ⁱⁱⁱ https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/aboriginal_torres_strait_islander_advance_care_planning.pdf?sfvrsn=2

^{iv} https://www.swslhd.health.nsw.gov.au/Carers/content/pdf/Advance_care_yarning.pdf

^v <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/taking-control-of-your-health-journey.pdf>

^{vi} <https://pepaeducation.com/pepa-mentors/indigenous-palliative-care-social-comic/>

4 | Recommendations

The *Summary Policy Paper* identifies facilitators of appropriate care in seven domains, underpinned by four key enablers (see p.2).

These domains and enablers are broadly consistent with the *National Palliative Care Strategy 2018* and other relevant policy documents. Recommendations arising from the project—including recommendations specific to Aboriginal and Torres Strait Islander peoples—are framed in this context.

The recommendations reflect a public health approach to palliative care (see *Summary Policy Paper* for details), which involves multiple sectors—from individuals and families to specialist palliative care service providers and broadly-focused, ‘non-traditional’ partners and collaborators.

These recommendations are designed to bolster the capacity of all relevant sectors to promote access to appropriate, quality palliative care for Aboriginal and Torres Strait Islander peoples with 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. As a concept, it incorporates respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers and access to care.²² For Aboriginal and Torres Strait Islander peoples, key components of person-centred care may include culturally-appropriate care and/or trauma-informed approaches (see *Summary Policy Paper* for more detail).

It is important to acknowledge that identifying and providing the elements necessary to

deliver person-centred care for people from under-served populations, including Aboriginal and Torres Strait Islander peoples, is likely to be particularly challenging and resource-intensive.

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

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, including Aboriginal and Torres Strait Islander peoples, are unlikely to succeed.

Palliative care providers may also need assistance from those with a greater understanding of the needs of Aboriginal and Torres Strait Islander peoples to co-design services and optimise person-centred care. Linkages between the palliative care sector and Aboriginal and Torres Strait Islander community and support organisations—i.e. those with existing relationships and experience meeting the needs of Indigenous people and communities—are likely to be of particular importance (see *Summary Policy Paper* for further discussion.)

Addressing facilitators of appropriate palliative care for Aboriginal and Torres Strait Islander peoples

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, health and social care providers.
- Provide culturally-responsive education around death, dying and grief, led by Aboriginal and Torres Strait Islander communities, groups and organisations.
- Assist health and social care providers to improve their skill and confidence in talking about these issues with Aboriginal and Torres Strait Islander peoples.

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 Aboriginal and Torres Strait Islander peoples (e.g. education sessions organised through existing support groups, engaging community leaders as 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 Aboriginal and Torres Strait Islander peoples

- Ensure all health and other relevant care providers are aware of and responsive to the potential impacts of the life experiences of Aboriginal and Torres Strait Islander peoples—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. Tailor resources to particular groups when required, and 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

- Facilitate the identification of Aboriginal and Torres Strait Islander people in palliative care settings to promote culturally-appropriate care.
- Bolster communities' capacity to deliver palliative care that is flexible, individualised and delivered in setting(s) of choice where possible. Consider:
 - Sufficient room for family to stay
 - Respect for rituals and ceremonies
 - Support for individuals to return to and/or die on country.
- Ensure appropriate setting design for Aboriginal and Torres Strait Islander communities, including accommodation options, decoration/displays etc. This includes identifying or creating an acceptable place/space to die.

- Consider and respect the role of families (as defined by individuals) and communities in decision-making and person-centred care.
- Embed cultural competency in relevant services (i.e. palliative care, primary care, aged care etc).

Better support advance care planning

- Build on current approaches to enhance advance care planning among Aboriginal and Torres Strait Islander peoples—particularly in specific settings such as primary care, aged care and disability support as well as palliative care.
- 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 the capacity of 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 Aboriginal and Torres Strait Islander peoples
 - 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, Aboriginal Health Services and other health and community care services as well as support organisations and other services providers as appropriate) to develop best-practice approaches to palliative care service delivery for Aboriginal and Torres Strait Islander peoples.
- Build relationships between palliative care providers and local leaders.

Workforce development

- Consider training and ongoing professional development initiatives that increase or improve health and social care providers':
 - Understanding of Aboriginal and Torres Strait Islander peoples (cultural competence)
 - Understanding of and ability to provide or support person-centred palliative care (e.g. through the PEPA program)
 - Knowledge of and skill applying trauma-informed approaches
 - Skill and confidence working with interpreters
 - Comfort and capacity to assist individuals with advance care planning.
- Employ Aboriginal and Torres Strait Islander staff, and consider creating identified positions.

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 Aboriginal and Torres Strait Islander peoples may be intensive in terms of both time and resources.
- Improve the alignment of the 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 Aboriginal and Torres Strait Islander peoples and evaluate efforts to improve access for these groups.
- Include activities relevant to Aboriginal and Torres Strait Islander peoples in palliative care quality improvement initiatives and organisational Reconciliation Action Plans (RAPs).

Abbreviations

Abbreviation	Definition
ACD	Advance care directive
AHA	Australian Healthcare Associates
AHW	Aboriginal Health Worker
ALO	Aboriginal Liaison Officer
GP	General practitioner
NDIS	National Disability Insurance Scheme
PEPA	Program of Experience in the Palliative Approach
RAP	Reconciliation Action Plan
the Department	Australian Government Department of Health

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.²³

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.²³

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.²⁴

End-of-life care: Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and other staff. 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.²⁵

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.¹

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.¹

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.¹

Person-centred care: Care that is 'respectful of, and responsive to, the preferences, needs and values of patients and consumers'.²²

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'.¹

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).²³

Trauma-informed care: 'An

organisational structure and treatment framework that involves understanding, recognising and responding to the effects of all types of trauma'.²⁶

References

1. Palliative Care Australia (PCA). *Palliative care service development guidelines*. (PCA, 2018).
2. NACCHO. Definitions. *Aboriginal health* (2017). Available at: <http://www.naccho.org.au/about/aboriginal-health/definitions/>. (Accessed: 27 Feb 2018).
3. Australian Bureau of Statistics. Estimates of Aboriginal and Torres Strait Islander Australians. (2018). Available at: <https://www.abs.gov.au/ausstats/abs@.nsf/mf/3238.0.55.001>. (Accessed: 21 May 2019).
4. Brooke, N. J. Needs of Aboriginal and Torres Strait Islander clients residing in Australian residential aged-care facilities. *Aust. J. Rural Health* 19, 166–170 (2011).
5. Australian Institute of Health and Welfare. *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015*. (Cat. no. IHW 147. AIHW, 2015).
6. Cancer Australia. *National Aboriginal and Torres Strait Islander Cancer Framework*. (Cancer Australia, 2015).
7. McGrath, C. L. Issues influencing the provision of palliative care services to remote Aboriginal communities in the Northern Territory. *Aust J Rural Heal.* 8, 47–51 (2000).
8. *Working together: Aboriginal and Torres Strait Islander health and wellbeing principles and practice*. (Commonwealth of Australia, 2014).
9. Palliative Care Australia. *Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians - Position statement*. (Palliative Care Australia, 2015).
10. Awofeso, N. Racism: A major impediment to optimal Indigenous health and health care in Australia. *Aust. Indig. Heal.* 11, 1–13 (2011).
11. Department of Health. *Caring for Forgotten Australians, Former Child Migrants and Stolen Generations: An information package for aged care services*. (Department of Health, 2016).
12. Australian Institute of Health and Welfare (AIHW). *Palliative care services in Australia*. (AIHW, 2017).
13. Australian Institute of Health and Welfare (AIHW). *Palliative care in general practice. Palliative Care Services in Australia* (AIHW, 2017).
14. Australian Bureau of Statistics. *2076.0 - Census of population and housing: Characteristics of Aboriginal and Torres Strait Islander Australians, 2016. Census of Population and Housing 2016* (2019).
15. McGrath, P. The living model: An Australian model for Aboriginal palliative care service delivery with international implications. *J. Palliat. Care* 26, 59–64 (2010).
16. O'Brien, A. P. *et al.* Considering Aboriginal palliative care models: The challenges for mainstream services. *Rural Remote Health* 13, 1–10 (2013).
17. McGrath, P. Family care giving for Aboriginal peoples during end-of-life: Findings from the Northern Territory. *J Rural Trop. Public Heal.* 7, 1–10 (2008).

18. Shahid, S., Bessarab, D., Van Schaik, K. D., Aoun, S. M. & Thompson, S. C. Improving palliative care outcomes for Aboriginal Australians: Service providers' perspectives. *BMC Palliative Care* (2013).
19. Williamson, M. & Harrison, L. Providing culturally appropriate care: A literature review. *Int. J. Nurs. Stud.* 47, 761–769 (2010).
20. Buck, K. *et al. Prevalence of advance care planning documentation in Australian health and residential aged care services, Short Report.* (Advance Care Planning Australia, Austin Health, 2017).
21. Waran, E., Wallace, S. & Dodson-Jauncey, J. Failing to plan is planning to fail: Advance care directives and the Aboriginal people of the Top End. *Med. J. Aust.* 206, 377–378 (2017).
22. Australian Commission on Safety and Quality in Health Care. *Patient-centred care: Improving quality and safety through partnerships with patients and consumers.* (ACSQHC, 2011).
23. Advance Care Planning Australia and National Ageing Research Institute. *Advance care planning in aged care: A guide to support implementation in community and residential settings.*
24. The Parliament of Australia. *Carer Recognition Act No.123, 2010.*
25. Australian Government Department of Health. *National Palliative Care Strategy 2018.*
26. Victorian Government Department of Health & Human Services. *Trauma and mental health: 10-year mental health plan technical paper.* (DHHS, 2015).