



Australian Government Department of Health

Exploratory Analysis of Barriers to Palliative Care

Issues Report on People Who Identify as
Lesbian, Gay, Bisexual, Transgender or Intersex

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

Acknowledgments

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Contents

Key messages.....	1	Figures and tables	
Barriers	1	Facilitators and underpinning enablers of quality palliative care.....	2
Promising approaches	1	Figure 1-1: Project activities.....	3
Recommendations.....	2	Figure 1-2: Suite of reports	4
1 Project background	3		
This report	4		
2 About this population group	5		
3 Findings.....	7		
Barriers to accessing palliative care	7		
Enablers and promising approaches	16		
Advance care planning	20		
4 Recommendations.....	23		
Addressing facilitators of appropriate palliative care for people who identify as lesbian, gay, bisexual, transgender or intersex	24		
Addressing underpinning enablers.....	26		
Abbreviations.....	27		
Glossary	28		
References	30		

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

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

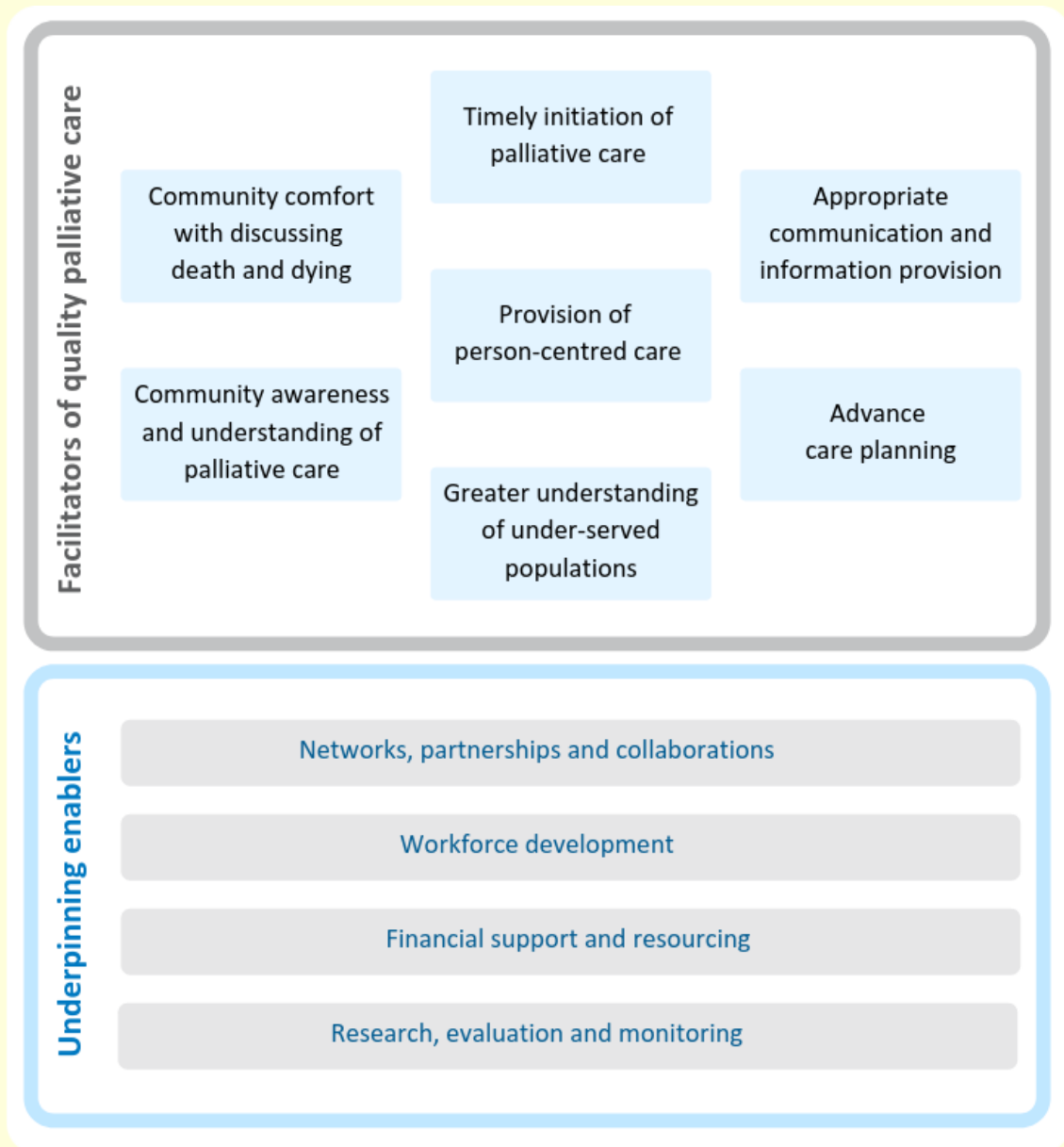
- Awareness-raising, especially around community-based palliative care
- Strategies to identify inclusive services (e.g. Rainbow Tick certification)
- Visible signifiers of inclusion
- Language that avoids heteronormative assumptions
- Recognition and inclusion of partners and chosen family, including legal recognition
- Access to advocacy services
- LGBTI-specific education and training for care providers

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

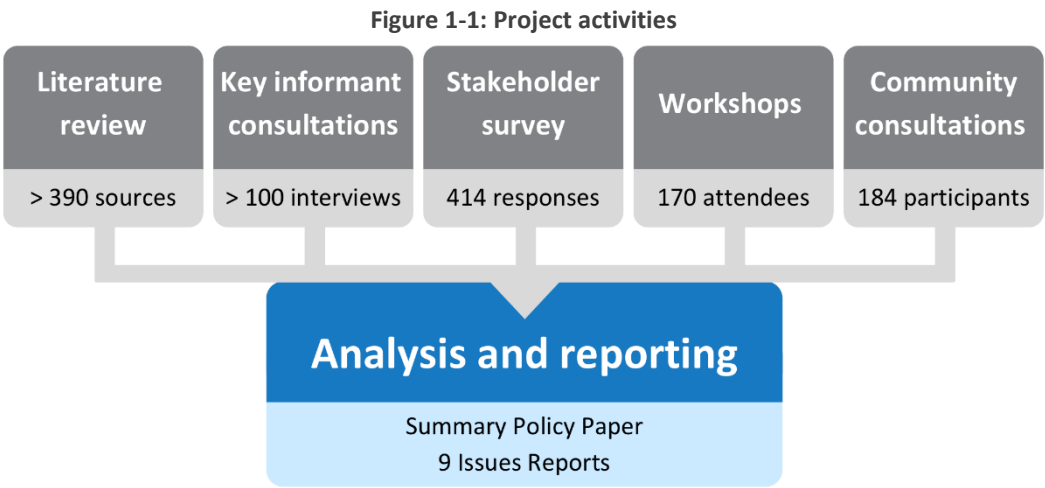
Australian Healthcare Associates (AHA) was engaged by the Australian Government Department of Health (the Department) in February 2018, to conduct an exploratory analysis of barriers to accessing quality palliative care for people from under-served populations or people with complex needs (the project).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



This report

This issues report describes key barriers and promising approaches for improving access to and experience of palliative care for LGBTI people 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 LGBTI people.

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

The umbrella term LGBTI is often used to describe individuals with ‘diverse sexual orientation, sex or gender identity’.² While difficult to estimate, several studies suggest that around 10-11% of the total population of Australia have diverse sexual orientation, gender identity or intersex characteristics.^{2,3}

While often seen as a single group, within ‘LGBTI’ there are ‘several distinct, but sometimes overlapping, demographics each with their own distinct histories, experiences and health needs’. Collapsing these separate groups into a single group in any analysis risks reaching conclusions that may not be relevant or appropriate for all groups.⁴

Lesbian, gay and bisexual

Lesbian, gay and bisexual people share a common experience of romantic, sexual, and/or emotional attraction to people of the ‘same sex’. While there are many important differences between these groups, issues around homophobia and heteronormativity were identified as the primary barriers to accessing quality palliative care—specific to this cohort, and thus they are mostly considered together in this report.

Transgender

Transgender (or trans) is an umbrella term used to describe people who do not identify with the gender they were assigned at birth. This includes people who identify with a binary gender (e.g. man, woman) and those who identify as non-binary (e.g. gender fluid, genderqueer, etc). Some trans people may seek medical gender transition while others may not. Some identify as trans while others simply identify as men or women. Some trans people may also identify as lesbian, gay or bisexual, while others identify as heterosexual.

Intersex

Intersex is a term to describe ‘people [who] are born with physical sex characteristics that don’t fit medical and social norms for female or male bodies’. The term does not indicate anything about a person’s legal sex classification, birth sex assignment, gender, gender identity or sexual orientation.⁵ Some intersex people may also identify as lesbian, gay or bisexual, but many identify as heterosexual. Some intersex people may identify their gender as intersex, while others may identify simply as men or women, as transgender, or do not identify with gender at all.

Context

While there are significant differences both between and within the different groups, LGBTI individuals share many common experiences—notably, stigma and discrimination for not fitting into heteronormative ideas of binary sex, gender, and sexual orientation.

Heteronormativity

Heteronormativity describes the way that that society is organised around heterosexuality as the ‘normal’ or default identity. It is predicated on the idea of gender as a binary concept, that is, the notion that there are only two types of bodies (male or female), and there is a straightforward alignment between all aspects of biological sex (chromosomes, hormones, and morphology), gender identity and expression, and sexual attraction. Heteronormativity includes norms around gender roles and underpins ideas about family, prioritising biological and marital relationships above all other types of connection.

LGBTI people face a number of barriers to accessing health care in general, and palliative care in particular. These barriers primarily relate to stigma and discrimination, along with heteronormative assumptions.

Trans people face significant additional barriers to accessing healthcare, including refusal of care by healthcare providers; gatekeeping of transition-related care; stigmatisation as mentally ill (a diagnosis of gender dysphoria—previously gender identity disorder—is usually required in order to access medical transition); inappropriate and invasive questions and comments; and service providers’ lack of knowledge about trans issues.

Intersex people face a different set of challenges around healthcare, including a history of ‘forced and coercive medical interventions, designed to make our bodies more typically female or male’⁶ which are routinely performed on intersex infants and children. These interventions can lead to a range of medical complications as well as significant psychological trauma related to loss of bodily integrity, autonomy and choice.⁶

While many LGBTI people live happy and healthy lives, many have (also) experienced rejection from their families and communities; discrimination in medical care, employment and housing; verbal and physical abuse; as well as more subtle but pervasive forms of discrimination (presumed heterosexuality, lack of representation, etc). As a result, LGBTI people as a group may be more likely than the general population to experience homelessness, poverty, and poor physical and mental health.^{4,7,8} They may be less likely to trust the healthcare system^{9,10} and other institutions, and may avoid or delay seeking medical care.^{11–13} These issues are especially pronounced for both trans and intersex populations.

It is perhaps not surprising, then, that LGBTI people as a group have a higher incidence of life-limiting disease (including a number of cancers).¹⁴ The literature also suggests that LGBTI people tend to present to palliative care services with more advanced disease¹⁵ than the general population. The findings discussed in this report help explain the reasons why, and identify strategies to address these issues.

3 | Findings

A number of the barriers, enablers and promising approaches to accessing palliative care that were identified through this project were actually *universal factors*, i.e. common to the general Australian population, rather than being specific to LGBTI people.

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 LGBTI people*.

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 LGBTI people and communities are heterogeneous, and, while findings and recommendations in this issues report are generalised, they are unlikely to be relevant in all cases.

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 healthcare 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.

Barriers to accessing palliative care

Consumer-side barriers

Individuals

As with other population groups, LGBTI participants had varied **understandings of palliative care**. In particular, the perception that palliative care was only delivered in institutional settings (such as a residential aged care facility, hospice or hospital) rather than in the home was a significant barrier, given the history of institutionalisation and discrimination against LGBTI people.

While **reluctance to talk about death and dying** was a universal barrier to accessing palliative care in a timely manner, many of

the LGBTI participants in this project indicated that they had discussed their wishes for end-of-life care with friends and family. This may reflect a greater awareness of death and dying among people who are LGBTI, compared with other under-served populations, and is consistent with the literature.¹⁶

The LGBTI community may have more experience of death than the general population due to disproportionately high suicide rate,⁴ and—especially for older gay men—individuals’ experiences of the HIV/AIDS crisis in the 1980s and 1990s (see *HIV/AIDS* on page 12). While these are a source of **collective trauma and grief**, they

may also mean that LGBTI people are more familiar, and comfortable, with the notion of death and dying than the general population.

A key barrier to access to palliative care for LGBTI people is a **perception that services are not appropriately sensitive or safe**. This perception is often based on experiences of discrimination in healthcare and other settings,^{15,17} awareness of other peoples' negative experiences, and/or heteronormative assumptions in how providers communicate.

'Heteronormativity makes normal certain sets of actions, ways of speaking and assumptions—just creating subtle exclusion' —Peak body representative

Stakeholders identified the **fear of discrimination and stigma** as especially significant for people living in rural and regional areas and for trans people, and is also likely to be a significant issue for intersex people.

'People come to Melbourne to access care. People are reluctant to get care [where they live] due to breaches of confidentiality which have had a major impact and created deep-rooted reluctance to access regional services' —Service provider

While the *fear* of discrimination is an 'internalised' barrier (hence included here under 'individual barriers'), discrimination

itself is a service-side barrier, and the responsibility—and ability—to address it lies with health and social care providers, palliative care providers and other organisations, rather than LGBTI individuals.

LGBTI people's concerns about discrimination applied not only to accessing services for themselves or their partner, but also in relation to supporting or visiting 'straight' family members in residential aged care or hospice settings, underscoring the ways that discrimination can negatively impact on everyone's care.

A number of participants were particularly concerned about discrimination from religious or faith-based service providers, and felt that they made up the majority of palliative care providers.

'Religious fear is a big issue for us' —Trans community member

Conversely, other participants pointed out that religious affiliation wasn't intrinsically antithetical to LGBTI people, that some LGBTI people are religious or spiritual, and that faith could be a source of comfort.

'[The] LGBTI community is perceived as anti-religious, but it's not true for all individuals. Religion can provide comfort at end-of-life' —LGBTI community member

LGBTI individuals who are concerned about discrimination may decide **not to disclose their status** to services and healthcare providers. This was especially apparent for people entering institutional care,¹⁸ and for people living in rural and regional areas.

Participants reported that some LGBTI people in rural and regional areas would prefer to travel to metropolitan centres for services rather than ‘out’ themselves to local providers.

‘Many people going into aged care go back into the closet, for fear of how they’ll be treated’ —LGBTI community member

Despite this, non-disclosure is unlikely to result in feelings of safety, since there is always the risk of being outed:

*‘For people who are not out, it is so stressful trying to hide’
—LGBTI community member*

For some people, **disclosure may not be a choice**. LGB people with same-sex partners may be recognised as a couple whether they want to be or not. Trans and intersex people may have even less choice about disclosure, their status revealed through medications (e.g. hormones), or ‘written on the body’ through anatomy and/or surgical scars (see *Service-side barriers* for further discussion).

One of the most prominent fears discussed by LGBTI respondents was the **fear of losing control** over their daily lives, their medical care and treatment, and their identities. For trans participants, loss of control was equated with the loss of dignity.

‘In the scenario that I had dementia and didn’t have control, I would be very scared of the family getting control, of not having a say in how I’d be buried, that I’d be subject to ridicule, that I’d be dishonoured in death. I would prefer not to suffer the humiliation’

—Trans community member

Loss of control is also likely to be a key barrier for intersex people, given the history of routine non-consensual medical interventions on intersex infants and children.

The fear of discrimination and loss of control was especially evident in relation to institutional care. Several participants expressed extreme **reluctance to enter institutional care**:

‘Given the choice, I’d go to prison over aged care because you get treated better’ —LGBTI community member

‘As a trans woman I have a fear of going into any palliative or aged care. At the focus group they were talking about euthanasia and I would definitely consider that’ —Trans community member

Family and community

LGBTI people may be more likely than the general population to be isolated from their birth families and from the general community.^{17,19} LGBTI people are also necessarily **excluded from heteronormative ideas of family**, and have defined **alternative models of kinship**—such as ‘family of choice’—in response.

‘Your friends are your family—[this is a] big element for LGBTI communities, as your biological family may have abandoned you’ —LGBTI community member

A number of participants spoke of the importance and strength of the LGBTI community, and particularly about community-driven palliative care in response to the HIV/AIDS crisis (see *page 12*). However, participants were mindful of the fact that individuals have different levels of connection to the LGBTI community, and that access to community supports was therefore uneven across the population. This is especially true for people who felt the need to hide their identity and/or the nature of their relationships.

Furthermore, **families defined by marriage or blood are prioritised** in healthcare settings or at end-of-life more generally.^{20,21} This may mean that an individual’s chosen family is not recognised as valid, or not valued as much as biological family. It also means the failure to recognise **family of choice** or acknowledge that ‘many LGBTI people have been ostracised or abandoned by their biological relatives, and that strong networks of friends and loved ones are as intrinsic and equally valid in the life of an LGBTI person with life-limiting illness’¹⁷.

‘It is a big issue that family of choice is not recognised’

—LGBTI community member

The **lack of recognition of LGBTI families** is a major barrier to accessing quality palliative care. This includes the failure to recognise or value same-sex relationships, even relatively ‘traditional’, long-term partnerships.

‘It’s so hard having to explain things every time a new person comes in. I am a lesbian woman and every time I’d have to explain who my partner is’

—LGBTI community member

By failing or refusing to recognise these relationships, health and social care providers may exclude partners from important discussions around diagnosis, treatment, and planning. Consequently, family and carers may experience **‘disenfranchised grief’** or bereavement marked by stigma and a lack of social recognition of loss. Compounding this, partners and caregivers can experience barriers to accessing bereavement support due to lack of recognition as well as inclusive services.

In some cases, prioritising traditional ideas of family may lead to LGBTI people being cared for by biological family members who may not support their gender identity or sexual orientation and therefore may make **inappropriate healthcare decisions**.²⁰ Again, this fear was particularly pronounced for trans people, and is likely to be a significant barrier for intersex people as well.

*‘Sometimes family can re-write what’s happened in someone’s last days’
—Trans community member*

LGBTI carers (or carers of LGBTI people) may experience **increased pressure and burden** if their loved one does not access palliative care services, or accesses them late. LGBTI people who are caring for their partners may also feel pressured to be exemplary carers in order to prove the validity or value of their stigmatised relationships:

‘[As LGBTI partners] we have a fear of not being good enough, fear of judgement’

—LGBTI community member

‘[I] always wanted to be seen as a partner, but now there is pressure to make formal decisions as next of kin [and that is] scary’

—LGBTI community member

HIV/AIDS

Issues related to HIV/AIDS inevitably inform any discussion of death, dying and palliative care in the LGBTI community. While the crisis of the 1980s and 1990s has passed, the impacts—including stigmatisation, collective grief and trauma, the loss of friends and elders, as well as the ‘custom of caring for your own’—continue to shape the community as a whole, and gay men in particular.

Several participants discussed the failure of the healthcare system to respond adequately or compassionately to the crisis.

‘People were dying in the streets...Due to lack of awareness, widespread stigma and discrimination and limited treatment options, a lot of LGBTI people used to come in very late—even hours from death’ —Service provider & LGBTI community member

While there have been substantial improvements in care over the last three decades, the memory or knowledge of this history may continue to influence LGBTI people’s decisions about whether and when they seek care.

‘The older generation, the population who may require palliation now, hesitate to use it...because their opinions about the health system have been shaped by their experiences in the 80s and 90s’ —Service provider

Participants also talked about the persistent ‘double stigma’ of being gay and HIV positive.

‘Ignorance is still a major issue in this day and age. We received a student who was HIV positive, and as part of his coursework had to get some work experience in care facilities. Somehow his status was leaked, which is against the law, and he was refused work at all five facilities he had targeted’ —Service provider

Despite advances in treatment that mean HIV is no longer necessarily life-limiting, being HIV-positive can make healthcare more complex, especially for individuals with other illnesses such as cancer.

‘Multi-morbidity is a major issue among HIV patients. Multiple diseases within a single patient compounds their problems and limits treatment options’ —Service provider & LGBTI community member

Several people raised the issue of neurodegenerative conditions associated with HIV, which can include early signs of dementia such as forgetfulness, confusion and anxiety.

‘As a result of neurodegenerative conditions, patients cannot communicate effectively, and this is the biggest barrier to palliative care—communication with medical professionals’ —Service provider

Service providers were concerned that these conditions are poorly understood and often overlooked, as they add ‘another layer of vulnerability to an already vulnerable population group’.

Service-side barriers

The most significant service-side barriers were related to **heteronormativity**, including implicit bias, presumed heterosexuality, and a lack of recognition, awareness and knowledge, and a lack of access to appropriate services and support.

Health care providers

LGBTI patients report experiencing **bias** across a range of healthcare settings and in palliative care in particular,²² if not clear **discrimination**.^{14,15} Healthcare providers may display **implicit preferences** for heterosexual people,¹⁵ and may have **difficulty communicating** with people about their sexuality and/or recognising people with diverse sex characteristics, sexual orientations, and gender identities.²⁰

Health and social care providers may **assume that their patients are heterosexual, cisgenderⁱ and endosexⁱⁱ**. This places a burden on LGBTI patients to correct these assumptions; however, many LGBTI people may be reluctant to disclose their status for fear of discrimination (see *Consumer-side barriers*).

Heteronormative assumptions may therefore delay or deny of the provision of person-centred care,²⁰ prevent the involvement of family of choice (see above) and result in partners being disenfranchised.²¹

‘We have a very heteronormative society. You only notice that when you’re on the outside. There is so much fear of being judged. If you have a partner, your sexuality is more obvious. If you don’t, heterosexuality is assumed’

—LGBTI community member

Participants noted that many health and social care providers **lacked knowledge or awareness** about LGBTI issues, particularly in relation to **trans and intersex health care**.

‘We need increased awareness of transgender issues by health professionals, [and to] develop an understanding of intersex variation—this is a medical condition, not an identity question’

—Peak body representative

ⁱ A person who identifies with the gender assigned at birth based on their physical sex characteristics.

ⁱⁱ A person born with physical sex characteristics that align with norms for female or male bodies.

Trans participants reported that a lack of awareness had resulted in **inappropriate comments** from health and social care providers. For example, one trans man recalled a nurse seeing his surgery scars and asking ‘*What have they done to you?*’ Another trans man was told ‘*They did a good job!*’ of his transition. Intersex people are likely to face similar issues.

Services or organisations

Participants reported a **lack of LGBTI-inclusive or supportive services**. This was based primarily on the perceived heteronormativity of most services, e.g. communicating heteronormative assumptions, or using **language, materials and resources that do not acknowledge and represent LGBTI experiences**.

‘People need to see people kissing/touching. Need to see that that’s normal...Need posters of people kissing—so people become OK with that. Need visible signs of safety’
—LGBTI community member

‘We need open communication between care providers and clients. Clients need to feel safe to disclose, need to know the organisation and care workers are LGBTI-friendly’
—Service provider

Lack of support for family and carers was also identified as a key issue, exacerbated by the lack of recognition of partners and family of choice (see *Consumer-side barriers*).

Bereavement care for partners has been identified as a key unmet need.¹⁹

Participants identified that it was important for organisations to have **anti-discrimination policies that explicitly included LGBTI issues**, but questioned how effective they were in practice.

‘All organisations have non-discrimination policies, like all schools have no bullying policies, but that doesn’t mean they’re upheld’
—LGBTI community member

*‘When you select a nursing home or hospice, the thing to look for is if they have policies about how they operate, whether they accept LGBTI people and any policies regarding how LGBTI people should be treated. However, **policies aren’t much use unless they are understood and implemented at the ground level** as well, otherwise you end up with a progressive manager or CEO who says all the right things but patients are still treated badly’* —LGBTI community member

Staff awareness and attitudes were seen to have more impact on service delivery than organisational policies. Participants attributed these issues to a **lack of training** in LGBTI issues and culturally-appropriate care. Some participants also connected this to the **perception of care work** as low-skilled (and low-paid), leading to a lack of investment in training and professional development, in high staff turnover and in

employment of staff not necessarily suited to caring roles.

Other patients and their families were also identified as a potential source of discrimination, underscoring the importance of enacting anti-discrimination policies at every level.

Healthcare system barriers

Although not unique to LGBTI populations, the **complexity of the healthcare system** and other sectors presented a significant barrier to accessing services for these groups. Participants reported that it was difficult to find relevant information and difficult to understand and navigate the various parts of the system (e.g. My Aged Care, NDIS, disease-specific organisations, etc).

In addition, LGBTI participants reported that it was difficult to find information about the LGBTI-inclusivity of individual service providers and facilities.

Legal issues were also a significant concern, including legal recognition of partners, chosen family, and decision-makers.

For trans people, legal concerns also included **legal recognition of their affirmed gender and name**.¹⁵

‘Disenfranchisement in LGBTIQ community—the choice for decision-maker is there—but that person may feel like they don’t have the voice or be silenced by family. The legal stuff is important in this context’
—Service provider

Enablers and promising approaches

Several participants reported positive experiences of palliative care, specifically in relation to the death of a parent. While these positive experiences weren't specifically related to being LGBTI, they served to highlight the importance of **person-centred care**.

Consumer-side enablers

As with all under-served population groups, and the general population, **education and awareness** about death and dying, and specifically about palliative care, would help enable LGBTI people to access quality palliative care in a timely manner. In particular, increasing awareness that **palliative care services can be delivered at home** (rather than in an institutional setting) would be of a benefit for the LGBTI community. Participants also noted that conversations about palliative care were typically aimed at older people, and indicated that education and awareness initiatives needed to **include young people**.

Strategies and resources for finding LGBTI-inclusive services were considered important. At the same time, the importance of such resources underscores the expectations of many LGBTI people that services may not be inclusive by default.

Access to **advocacy** was seen as essential to redressing issues with service provision.

The **presence of family** was seen as a factor in the quality of care provided by services, particularly in residential settings.

'While dealing with family is difficult...having family members who visit regularly can work in your favour. In my experience, people who get regular visitors are better cared for in hospices or aged care facilities than those who do not'

—LGBTI community member

While the community member quoted above was referring to biological family, this could also apply to regular visits from chosen family—especially if services **recognise the validity of alternative models of kinship**.

Although not universal, some sectors of the LGBTI community have developed a strong 'custom of caring for your own', including community care, peer support, and resource development and sharing (see p.12). There is also a strong tradition of LGBTI activism and advocacy, which has been effective in changing perceptions, policy and service delivery for intersex, transgender, and same-sex attracted people and for the general population (e.g. through harm minimisation, prisoner health, safer sex education, mental health and suicide prevention initiatives).

This suggests there is a high degree of **community support and resilience** that LGBTI people may be able to draw on. However, participants were mindful of the fact that LGBTI people as a whole may be more likely than the general population to experience social isolation, and noted that individual LGBTI people have different levels of connection to their communities (LGBTI and otherwise).

In addition, strong community support and resilience does not mean that more formal and systematic support isn't necessary. Rather, the development of these supports indicates that there is, in fact, a **significant unmet need** that the community is seeking to address.

At the same time, strategies to improve access could make use of the **strong community supports already in place**, e.g. peer support services such as the [Gay and Lesbian Switchboard](#),ⁱⁱⁱ AIDS councils, etc.

'HIV services have been built up around empowerment and nurse advocacy, but palliative care services have not been built in this way' — Service provider

Indeed, the Victorian AIDS Council (now Thorne Harbour Health), in partnership with Bolton Clarke, has provided palliative care support for several decades. This service began in response to the HIV/AIDS crisis and has expanded to include the entire LGBTI community (see *next page*).

'Look at Australia's response when people were dying of HIV. Palliative care was provided with comprehensive partnership approaches back then. That has now vanished. Go back and look at that. We don't need to re-invent the wheel—that was a best-practice approach'
—Service provider

ⁱⁱⁱ <http://www.switchboard.org.au/>

Thorne Harbour Health and Bolton Clarke partnership model

The Thorne Harbour Health (THH) and Bolton Clarke (BC) partnership model provides palliative care support for LGBTI people with a life-limiting illness who wish to die at home. Care is provided mainly by volunteers, with support from THH staff and BC nurses. Services are provided across Victoria and are seen as especially vital for rural and regional residents.

The model is a community-driven response to the health system's perceived failure to meet the needs of people living with HIV/AIDS—including, but not limited to, members of the LGBTI communities (see HIV/AIDS on *page 12*).

The partnership was initially established by the Victorian AIDS Council (now Thorne Harbour Health) and the Royal District Nursing Service (now Bolton Clarke) in 1990, following a one-year pilot program. THH was responsible for recruiting and managing volunteers, while BC provided dedicated nursing support for clients, as well as training—including aspects of clinical care—for volunteers.

As HIV mortality rates have declined, the model has evolved to include all LGBTI clients who require community palliative care, in addition to those living with HIV/AIDS.

The characteristics of volunteers have changed in parallel. In the 1990s, volunteers were predominantly individuals who had been affected by HIV/AIDS. Now, volunteers are mainly young university students who may or may not identify as LGBTI.

The amount and type of support has also changed. At the height of the AIDS crisis, a

client could have as many as 14 volunteers providing around-the-clock care. BC nurses also made regular visits to clients and provided 24-hour phone support for volunteers. Now clients receive an average of 3-6 hours of volunteer assistance each week, mainly involving emotional and practical support such as cooking, housework, and transport to appointments (especially important for rural and regional clients). BC nurses still visit to provide clinical care and refer to specialist palliative care services when required. Clients who are at the end-of-life stage may receive additional volunteer support (up to 12 hours per week), as well as *'paid attendant care at home, to keep people where they want to be'*.

The THH-BC model also supports families and volunteers after the death of a client, with counselling and debriefing offered to volunteers.

The model provides effective services to a wide range of clients with multiple intersecting vulnerabilities. For example, clients who are experiencing homelessness can provide THH's mailing address as their own address in order to access services. The partnership model also expands the available networks and can help clients access specialised services and navigate the various care systems (e.g. NDIS, My Aged Care).

While representatives from THH and BC would like to see increased funding for the service, they also note that if stigma and discrimination by health services toward people who are LGBTI was addressed effectively at a systemic level, such specialist services would not be required for the community.

Service-side enablers

The primary factor in enabling LGBTI people to access high-quality palliative care is **inclusive services**.

Some things **mainstream services** can do to provide inclusive services include:

- **Visibly signify** inclusivity
- Use **inclusive communication** and **language that avoids heteronormative assumptions**
- Develop **policies** that are consistently translated into **practice**
- **Recruit staff and volunteers** from the **LGBTI community**
- Ensure all staff are **culturally competent** and **trained** in LGBTI issues
- Recognise and **respect non-traditional forms of kinship**
- Develop **partnerships with LGBTI organisations**
- Undertake **training and certification**, such as Rainbow Tick.

‘I did the How2 program run by Gay and Lesbian Health Victoria, and realised more was needed than just staff awareness. During this process I became aware that LGBTI-inclusive practice is a lot more than just education’ —Academic

‘The processes by which people are excluded are not obvious. You are completely oblivious to the fact that your forms are not being inclusive’ —Peak body representative

Given that history of trauma is common among LGBTI people, **trauma-informed approaches** are also relevant to the palliative care setting and its workforce.

Trauma-informed care is based on the knowledge and understanding of how trauma affects people’s lives, and seeks to avoid re-traumatising patients (see the *Summary Policy Paper* for more detail).

Some respondents also expressed a desire for **LGBTI-focused services**, including residential care facilities ‘with a community feel’. However, the general feeling was that it would be better to have genuinely inclusive services across the board:

‘Many cultural groups have their own, dedicated aged care homes and assisted living facilities. There’s a good reason for this, as such facilities are culturally safe and competent for them. I am not saying that gay men need their own facilities, but if better cultural competency standards are imposed across the board, it will eliminate the need for special or separate facilities for anyone’ —Peak body representative

Resources

There are numerous **resources and training opportunities** which health and social care providers and organisations can access to improve cultural competency around LGBTI care. Some of these include:

- Rainbow Tick certification
- The LOVE Project (ACON Ageing Initiative)²³
- Silver Rainbow
- AIDS councils (state/territory)
- Gender centres (e.g. Zoe Belle in Vic, The Gender Centre Inc in NSW, etc)
- National LGBTI Health Alliance
- Val’s Café/How2
- GLBTI Rights in Ageing Incorporated (GRAI)
- Intersex Human Rights Australia (IHRA).

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.²⁴

The consultations and literature highlighted **formal advance care planning as especially important** for LGBTI people.^{25–27} Despite the perceived importance, studies indicate that while more than half of LGBTI individuals have discussed their end-of-life preferences with their partner, few have an ACD.

The primary reason for formal advance care planning was to **guard against the possibility of family members and healthcare providers disregarding their wishes**.¹⁴ This was especially true for trans participants—although one study found that trans people were 50% to 70% less likely than LGB people to have formal arrangements in place.²⁸

This is compounded by issues around the **recognition of an individual's chosen substitute decision-maker** (often partner) as opposed to 'next of kin', particularly when there is disagreement between the dying person's family of origin and their same-sex partner.²⁹ Research suggests that healthcare providers may often be **uncertain or make incorrect assumptions** regarding who the **legally-authorised decision-maker** is.³⁰ This highlights the importance for LGBTI people of

formally appointing a substitute decision-maker, enduring power of attorney, and/or enduring guardian.

'Even if patients declare who they want [as appointed decision-maker]—the medical staff may still give preferences to family over partners'
—Service provider

Other reasons for advance care planning included reducing the burden of decision-making on loved ones²⁷ and minimising the disenfranchisement of partners.²⁹

'We need to talk more about death and dying. Yes, I have spoken with family about death and dying. But it's fraught—my son doesn't want to make decisions, I tell him he won't have to, I'll have an ACD'
—LGBTI community member

'I think they're very empowering, the fact that you have a document ready brings confidence to people that their wishes about end-of-life are now on paper...It is extremely confusing and confronting for families and can often lead to tension and conflict, which isn't good for the patient'
—LGBTI community member

Barriers to advance care planning

Many of the barriers to palliative care access described earlier also apply to advance care planning, including discrimination, stigma and disenfranchised grief, as well as lack of knowledge and a reluctance to think about issues related to death and dying.

‘Lots of people have the form but are yet to complete it, because they don’t want to accept getting older’
—LGBTI community member

Consultations also identified the **confusion around complex formal planning processes**—and the attendant paperwork—as a significant barrier.

‘Yes, I have made an advance health directive. But it’s really confusing to do. Very complicated’
—LGBTI community member

‘After filling out all the forms—I still walked away with six more forms’
—LGBTI community member

The complexity was compounded by **differences in options, processes and terminology and laws in each jurisdiction**.^{25,26}

Estrangement from biological family was also identified as a barrier to advance care planning for LGBTI people.

‘One systemic barrier is that LGBTI people often have no kids, and they’re estranged from birth families, leaving no one to trust with the ACD’
—LGBTI community member

Another barrier identified in the consultations was the perception that an individual’s wishes may be **ignored or disregarded** even when formally documented in an ACD:

‘I know that doctors or ambulance can still choose to override it and act to revive or resuscitate. They’re not legally bound’
—LGBTI community member

‘My niece is my power of attorney for the ACD, but having a power of attorney and ACD is no guarantee that things will be smooth’
—LGBTI community member

As a result, some people may see ACDs as ‘pointless’, or at least not worth the considerable effort required to prepare them.

Enablers of advance care planning

As with barriers, many of the enablers of access to palliative care discussed above also apply to advance care planning.

Several participants reported positive experiences of attending **information sessions** on advance care planning and how to complete an ACD. This highlights the importance of **education to raise awareness** of end-of-life care planning options among LGBTI people, and **increasing health and social care providers' preparedness to discuss advance care planning** with this population group.²⁵

One participant identified younger people as a driving force in increasing awareness and uptake:

'Increasing numbers of young people with terminal illness have completed ACDs and are leading the charge for change, but the older people are still afraid' —LGBTI community member

Some researchers suggest that the **legalisation of same-sex marriage** is likely to have a positive effect on palliative care issues for LGBT people,³¹ particularly in relation to the legal status of same-sex partners.²⁵ However, this only applies to couples and does not address the issues of recognising chosen family. Furthermore, people should not be forced to marry in order for their relationship to be validated. It is thus vital that marriage is **not the only means to legal recognition**.

Finally, one of the perceived benefits of completing a formal ACD was that the process/resources/template could prompt consideration and discussion of the types of care available.

This suggests that ACDs could potentially be an enabler for advance care planning and for palliative care in general.

'Advance care directives can be helpful with examples of types of care listed that can help guide you' —LGBTI community member

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 LGBTI people—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 LGBTI people 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.³² For LGBTI people, 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 people who are LGBTI, 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 LGBTI people and other under-served population groups are unlikely to succeed.

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

Addressing facilitators of appropriate palliative care for people who identify as lesbian, gay, bisexual, transgender or intersex

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.
- Assist health and social care providers to improve their skill and confidence in talking about these issues with people who are LGBTI.

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 people who are LGBTI (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 people who identify as lesbian, gay, bisexual, transgender or intersex

- Ensure all health and social care providers are aware of and responsive to the potential impacts of the life experiences those who are LGBTI—in particular the increased likelihood of trauma.
- Increase health and social care providers' awareness and knowledge of trans and intersex health care.
- Promote cultural understanding, while avoiding cultural stereotyping.

Improve communication and information provision

- Avoid heteronormative language and assumptions in personal communication, forms, and promotional material.
- 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
 - Visible indicators of inclusiveness
 - 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, including visible signs of inclusiveness of LGBTI people.
- 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).
- Engage with LGBTI communities to co-design services.
- Ensure organisational policies and culture are inclusive, and include effective procedures for addressing discrimination and breaches of privacy.

Better support advance care planning

- Build on current approaches to enhance advance care planning among those who are LGBTI—particularly in specific settings such as primary care, aged care and disability support as well as palliative care.
- Develop initiatives to support LGBTI people and organisations to understand current legal rights.
- 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 people who are LGBTI
 - 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 best-practice approaches to palliative care service delivery for LGBTI people.

Workforce development

- Consider training and ongoing professional development initiatives that increase or improve health and social care providers':
 - Understanding of possible needs of people who are LGBTI (cultural competence)
 - Understanding of 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.

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
- Improve the alignment of the relevant funding systems (including NDIS, aged care, primary and other healthcare) 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 LGBTI people and evaluate efforts to improve access for these groups.
- Include activities relevant to people who are LGBTI in palliative care quality improvement initiatives.

Abbreviations

Abbreviation	Definition
ACD	Advance care directive
ACON	AIDS Council of NSW
AHA	Australian Healthcare Associates
AIDS	Acquired Immune Deficiency Syndrome
BC	Bolton Clarke
GP	General practitioner
HIV	Human Immunodeficiency Virus
LGBTI	Lesbian, gay, bisexual, transgender or intersex
LOVE Project	Living Older Visibly and Engaged Project
PTSD	Post-traumatic stress disorder
the Department	Australian Government Department of Health
THH	Thorne Harbour 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.³³

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.³⁴

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.³⁵

Cisgender: A person who identifies with the gender assigned at birth based on their physical sex characteristics.

Endosex: A person born with physical sex characteristics that align with norms for female or male bodies.

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.³⁶

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 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'.³²

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).³³
- **Trauma-informed care:** 'An organisational structure and treatment framework that involves understanding, recognising and responding to the effects of all types of trauma'.³⁷

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