Brisbane North PHN

Palliative Care Needs Assessment

Final Report

Prepared by Create Health Advisory

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We sincerely acknowledge the Jagera, Turrbal, Gubbi Gubbi, Waka Waka and the Ningy Ningy peoples as the Traditional Custodians of the lands, waterways and skies, and we pay our respects to their Elders past and present.

As we discuss palliative and end-of-life care, we specifically recognise the enduring spiritual connection to Country, a relationship that encompasses all of life and informs the journey of passing – understanding that for many First Nations people, the option to pass on Country is a vital and sacred aspect of a good death, and we honour the ancient wisdom in caring for community across all stages of life’s journey.

Table of Contents

List of Acronyms and Abbreviations

ABS	Australian Bureau of Statistics
ACCHO	Aboriginal Community Controlled Health Organisation
ACP	Advance Care Planning
BNPCC	Brisbane North Palliative Care Collaborative
COPD	Chronic Obstructive Pulmonary Disease
DVA	Department of Veteran’s Affairs
GPs	General Practitioners
LGA	Local Government Area
LGBTIQA+	Lesbian, Gay, Bisexual, Transgender, Intersex, Queer , Asexual
MNHHS	Metro North Hospital and Health Service
NDIS	National Disability Insurance Scheme
PEPA	Practical Experience in the Palliative Approach
PTSD	Post Traumatic Stress Disorder
RACH	Residential aged care homes
SA3	Statistical Area 3
SEIFA	Socio-economic indexes for areas
The PHN	Brisbane North PHN
The Queensland Strategy	The Queensland Government's Palliative and End-of-Life Care Strategy
The Report	The Palliative Care Needs Assessment
The Strategy	The Commonwealth’s National Palliative Care Strategy
VAD	Voluntary Assisted Dying

Executive Summary

The Palliative Care Needs Assessment (the Report) for Brisbane North PHN (the PHN) represents the first comprehensive assessment of palliative and end-of-life care needs across the North Brisbane and Moreton Bay region. Palliative care is increasingly recognised as an important area of health need across the community, with demand expected to rise substantially over the next decade, driven by an ageing and growing population, changing disease profile and medical advancements. The complexity of palliative and end-of-life care is also increasing, driven by changes to government policy including Voluntary Assisted Dying (VAD), greater recognition of the nuanced needs of priority cohorts and contemporary approaches to holistic care that are prompting Australians to rethink traditional medical models of care.

To better understand palliative health care across the region, this Report examines the prevalence, demographics, health needs, current services and barriers to palliative and end-of-life care. The Report draws on publicly available research, quantitative data analysis and service provider, consumer, carer and peak body interviews from across the North Brisbane and Moreton Bay region in October and November 2025. Together these inputs have informed 27 key findings across five key areas of inquiry.

Part 1: Prevalence and demographics of palliative care across the region

The North Brisbane and Moreton Bay region will experience increasing demand for palliative and end-of-life care across the region, driven by a 30 per cent growth in the population predicted over the next decade and an ageing population (who have an increasing need for palliative and end-of-life care). There are notable differences in the leading causes of death and complexity of conditions across the region's geographical and demographic profile, as well as variation in the underlying health causes requiring palliative care among priority cohort groups. This is important to understand as specific needs, symptoms and care pathways can vary depending on the reason for palliative care.

Key Findings:

1	**Population growth and ageing** -The North Brisbane and Moreton Bay region has a population that is both growing and ageing-which will drive a significant increase in the demand for palliative and end-of-life care over the next decade. While demand will grow across the entire region, it is expected to significantly increase in the urban fringe including the North Lakes, Caboolture and Narangba – Burpengary areas.
2	**Leading causes** - The leading causes of death requiring palliative care for people living in the region is varied, and includes cancer, coronary heart disease, cerebrovascular diseases (stroke), dementia and respiratory disease. There are some differences in palliative care needs by gender, with breast cancer a leading cause of death for females and prostate cancer for males. Dementia is the leading cause of death for females and second leading cause of death for males in the region, and is often overlooked in palliative care.
3	**Age profile** - While the majority of persons requiring palliative and end-of-life care are older (approximately 60 per cent are over 65 years), there is a need for palliative care services across all age cohorts.
4	**Priority cohort differences in leading causes** - Some priority cohort groups have differences in the health causes of palliative and end of-life care - including First Nations Australians, people with disability and veterans compared with the general population. Some priority groups face significant complexity due to wider social determinants that may impact their palliative and end-of-life care needs, for example those who are incarcerated and those experiencing, or at risk of, homelessness.

Part 2: Current palliative care services in the region

Palliative care services in the North Brisbane and Moreton Bay region are delivered across a fragmented system of home-based care, residential aged care homes (RACHs), hospices and hospitals, with a clear gap between consumer preference and service reality. Despite 90 per cent of Australians preferring to receive palliative care at home and 50 per cent wanting to die at home, the national dying-at-home rate of only five per cent (two per cent in Queensland) suggests that the current system fails to support this preference due to a range of factors including constraints in primary care workforce and funding for personal support.

Three specialist services offer home-based palliative care support in the region, however cost, complexity and limited capacity for breakthrough pain management drive many to hospital. The region has 87 RACHs, significantly above the state average, where about 30 per cent of all deaths occur, however a persistent gap exists in embedding palliative care into routine practice. Notably, there is one children's hospice in the region (servicing Queensland), but no dedicated adult hospice service, a gap service providers identify as a key reason why hospital settings remain the primary location of death. The eight hospitals offering specialist services have a high rate of palliative care-related admissions, exceeding state and national averages.

Key Findings:

5	**Service profile** - The Brisbane North PHN region includes three specialist palliative care services which provide home care, one children's hospice and seven public and private hospitals which provide adult specialist palliative care. These services are also supported by a wider service system of residential aged care homes, community pharmacies, general practices, additional hospitals and urgent care clinics.
6	**Identified service gaps** - Service gaps reported in palliative and end-of-life care for the region include adult hospice services, transition from child and youth services, and appropriate end-of-life spaces that accommodate different cultural and family needs.
7	**Inadequate support for home based palliative care** - While there is a strong consumer preference to receive palliative and end-of-life care at home, only a small number of people actually die at home, with the majority dying in a hospital setting. The North Brisbane and Moreton Bay region has higher hospital admission rates for palliative care than both the national and Queensland average.

Part 3: Needs and circumstances of those requiring palliative care

Consistent with Australian research, the North Brisbane and Moreton Bay region faces significant challenges in relation to death and grief literacy and fear around death and dying which limits proactive involvement in end-of-life planning and holistic care, including spiritual and psychosocial support. Service providers stress the need for culturally appropriate and trauma informed care that acknowledges the unique and spiritual needs of diverse populations, moving beyond a medically centred approach. Consumer choice and control in end-of-life care is important, however further work is needed to support advance care planning, timely access to VAD where that is chosen, supporting non-traditional approaches and beliefs, trauma processing and life review and understanding consumer rights and choices.

Navigating individual choice and nuanced needs often requires the family or primary carer to be the health advocate at end-of-life stages. There are a range of specific care needs and challenges which may arise, particularly for priority populations which need to be considered to ensure a positive palliative care experience. The specific needs, trauma, stigma and discrimination that may exist for individuals who identify with one or more priority cohorts needs to be well understood and addressed by health professionals and the wider workforce that support palliative and end-of-life care.

Key Findings:

8	**Death and grief literacy** - There is a need to improve death and grief literacy across the community and with health practitioners. This can be a significant barrier to effective spiritual care, advanced care planning, and death and funeral planning.
9	**Consideration of new approaches** - Contemporary and consumer-based approaches to end-of-life and death care could be improved across the region.
10	**Carer health advocacy** - Carers and families report needing to provide health advocacy and act as the point of contact and communication for people at the end-of-life stage.
11	**Specific needs of socially isolated consumers** - Those who are socially isolated and who do not have family and carer supports have been identified as a priority group who may face challenges in accessing effective end-of-life care, exercising choice and control, and support in death planning. Models of care that provide strengthened care coordination, health advocacy and death planning need to be considered for this group.
12	**Priority cohort nuanced needs** - There are specific palliative care needs and challenges for some priority cohort groups, including but not limited to: • incorporating cultural and spiritual values and traditions • language barriers to accessing care and utilising choice • social isolation • overshadowing • non-inclusive environments

	• supporting guardianship and decision-making • late identification of palliative care needs • a lack of trauma informed approaches • addressing systemic bias and discrimination (including understanding how historical experiences of discrimination and bias might impact on individuals requiring care).

Part 4: Healthcare supply and service provider barriers

Service provision in palliative and end-of-life care is significantly constrained by workforce shortages, particularly due to a projected shortfall of palliative medicine specialists and ongoing challenges in recruiting and retaining community palliative nurses. There is also a need to improve the education and training of the workforce, both in upskilling to provide speciality palliative and end-of-life care services and to support the wider health and social care workforce in understanding, identifying and referring into palliative and end-of-life care services. Workforce models are also shifting to reflect more holistic approaches to care, including the roles of death doulas and grief and bereavement counsellors.

Funding models are insufficient, fragmented and not timely which impact on the options available to consumers and their families, often leading to avoidable hospital admissions. Care coordination and referral systems across the North Brisbane and Moreton Bay region rely on relationships across the network between service providers and could be strengthened to improve the consumer experience particularly the initial access and referral into specialist palliative care where required. In addition, the medical model of palliative and end-of-life care may be leading to late referrals and overservicing at end-of-life stages.

Key Findings:

13	**Workforce shortages** - Ensuring a sustainable palliative care health workforce remains a key challenge and may worsen in light of growing service demand. Education and training of the workforce in culturally safe palliative and end-of-life care remains a priority.
14	**Emerging workforce roles** - Palliative and end-of-life care models need to consider the emerging workforce including death doulas and grief and bereavement counsellors in providing holistic and consumer centred care.
15	**Scope of practice** - Workforce models in community settings need to consider scope of practice restrictions, particularly in relation to the administration of breakthrough medications and the clinical risk associated with safe care.
16	**Funding gaps for adult services** - Funding models do not support those over 18 years and under 65 years to receive community based palliative care, and often rely on family and carer support, adding financial pressure to families.
17	**Other gaps in funding** - Financial and funding gaps also exist for those over 65 who are not receiving aged care funding, refugees and non-Australian residents.
18	**Funding delays for aged care and National Disability Insurance Scheme (NDIS) recipients** - Service providers report a significant delay of 3-6 months in the approval to upgrade aged care and NDIS packages to include palliative care impacting on timely funding available to service providers. It is noted the aged care changes to take effect from 1 November 2025 may assist in addressing these delays.
19	**Reasons for hospital referral** - Referral into hospitals for end-of-life care often occurs due to end-of-life medication needs, inadequate funding to support personal care at the end-of-life, and other clinical and socio-economic complexities.
20	**Referral pathways in the region** - Referral pathways between key service providers within the North Brisbane and Moreton Bay region are reported as inconsistent and reliant on existing relationships and knowledge.
21	**Delays in referral into palliative care** - Early referral to palliative care is often impeded by health professionals' reluctance, which may stem from a perception of medical failure.

Part 5: Health service utilisation and consumer barriers

The increasing demand for palliative care is met with some systemic failures that result in delayed access, including around funding models and access, available services and settings, and navigation and community awareness. These systemic failures are often acutely felt by complex cohorts, particularly adults under 65 who don't receive funding under the NDIS or aged care systems, leaving them without support for home-based care.

Consumers and carers struggle with service navigation, lacking awareness of available resources and facing distress when primary care providers question hospital-prescribed palliative medications. Access can also be hindered by travel and cost barriers, with the service system not always supporting home-based visits (such as from General Practitioners (GPs)) and the out-of-pocket costs of medications, equipment and workforce often limiting the option to provide palliative care in the home. While the PHN have implemented several projects to support medications access in the community and provide palliative care resources for those living in the region, awareness of these resources remains low.

Key Findings:

22	**Delays in access** **-** There is evidence of delays in being able to access palliative care services. This is due to various factors including assessment and intake processes to receive palliative care funding, lack of awareness and navigation issues, and service capacity.
23	**Information and access** **-** Stakeholders and consumers reported a preference to access a single, reliable and complete source of palliative and end-of-life care information and service available within the North Brisbane and Moreton Bay region.
24	**Handover experience** **-** Gaps in health professional communication and handover can lead to confusion, stress and an additional carer burden for end-of-life consumers and their families.
25	**Travel constraints** **-** Travel demands increase the physical, emotional and financial strain on both patients and carers, particularly when frequent appointments are required.
26	**Consumer cost burden** **-** The financial cost burden is a significant barrier in accessing home-based palliative and end-of-life services, including medication costs, equipment and dressing costs, and personal carer workforce costs.
27	**Palliative medications** **–** Access to palliative medications in the community has been a previously identified barrier to home based palliative care. The PHN have sought to strengthen access to palliative medications in the community through the targeted and active commitment of selected community pharmacists to stock medications to ensure timely access for consumers.

Conclusion

This Report shows that palliative and end-of-life care is an area of growing need across the North Brisbane and Moreton Bay region. It includes complex considerations which include the needs of priority cohort groups, and a need to reflect holistic consumer-centred models and contemporary settings and approaches.

The findings across this Report lend themselves to the following key recommendations to strengthen existing services and experiences and address systemic gaps:

- exploring the viability of an adult hospice for the region and improving access to home-based models of care
- improving education and training in relation to priority cohort palliative care and end-of-life needs
- enhancing contemporary and consumer led models of care
- improving death literacy and enabling a Compassionate Communities approach including promoting awareness of extensive place-based resources in relation to palliative care
- consideration of a palliative care digital front door for the region
- improving data collection.

While opportunities exist for improvement, the dedication, contemporary perspectives, compassion and care of those working for and with palliative consumers across the North Brisbane and Moreton Bay region suggest a positive future.

Introduction

Purpose

This Report details the findings from analysis undertaken by Create Health Advisory on behalf of the PHN on the palliative care needs and services across the North Brisbane and Moreton Bay region, as at November 2025.

The Report draws on a mixed methods approach including existing quantitative data and qualitative insights drawn from consultation with service providers, consumers and other relevant stakeholders from the region (as outlined in Appendix A).

It is important to note the Report seeks to draw out the palliative care needs of priority cohort groups including, but not limited to:

- Aboriginal and Torres Strait Islander people
- people from culturally and linguistically diverse backgrounds
- refugees
- people who identify as Lesbian, Gay, Bisexual, Transgender, Intersex, Queer , Asexual (LGBTIQA+) (including Sistergirl and Brotherboy)
- people with disability
- socio-disadvantaged population (including those experiencing, or at risk of, homelessness)
- younger persons with palliative care needs (under 18 years old for this Report (1))
- those with neurodegenerative conditions including people with dementia
- Stolen Generation, Care Leavers and Forgotten Australians
- people who are incarcerated
- veterans.

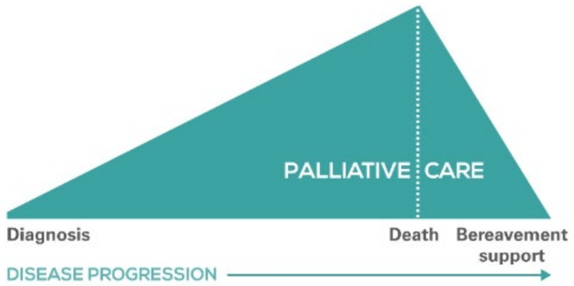
Definitions

Palliative Care

It is acknowledged that there are varying definitions of palliative care used across Australia. For the purpose of this Report, a broad definition has been adopted to capture a holistic view of the needs and services across the North Brisbane and Moreton Bay region. Palliative Care has therefore been defined as:

Care for patients with life-threatening illnesses that aims to prevent, identify, assess, relieve or treat the person's pain, discomfort or suffering in order to improve their comfort and quality of life. Palliative care does not end with death and is also inclusive of caring for the families who are experiencing grief and bereavement and helping to also relieve their physical, psychosocial and spiritual suffering, as in Figure 1. (2) (3)

Figure 1: Palliative Care needs from the point of diagnosis through to grief support following death (2)



End-of-life Care

It is important to note the distinction between palliative care and end-of-life care. Palliative care is often associated with end-of-life care, however it is available to any person living with a life-limiting illness at any stage of disease progression. End-of-life care is a subset of palliative care in which care is provided to people and their families who are imminently facing the end of their life and likely to die within the next 12 months. (4) The 12 month period is variable across jurisdictions but across Queensland, death within 12 months is generally considered end-of-life.

Context

The need for person-centred palliative care that is responsive to diverse community needs is a critical and growing priority for healthcare systems, particularly in regions like Brisbane North with its significant older population.

While palliative care can occur across any age cohort, there is an increase in palliative care needs for older Australians. As of December 2023, the PHN region had an ageing cohort (aged over 65 years) of approximately 170,000 people, which grew at a rate of 24.5 per cent between 2016 to 2022. (5)

The need to strengthen palliative care models is also being driven by a need to reduce unnecessary hospitalisations, challenges in residential aged care capacity, improvements in technologies that allow for remote monitoring, and supporting individuals to access care in the most appropriate setting for their needs.

Other more recent trends in palliative care both within Australia and worldwide include the interface of palliative care with VAD; reflecting the needs of younger people with palliative care needs; a focus on the role of carers and families including the need for bereavement support; and assessing the cost effectiveness of models that support dying at home.

This occurs in the context of an estimated 50 per cent increase in the expected demand for palliative care services in Australia by 2035, driven by the growing number of people living longer with chronic disease and life limiting illnesses combined with an ageing population. (6)

Nationally, palliative care priorities include the need to address siloing and communication between health service providers to provide seamless care. This is leading to an increasing focus in the policy and service delivery landscape on providing collaborative and integrated palliative care services that combine local acute and community health services and provide integrated care to the consumer.

The National Palliative Care Strategy 2018

The current National Palliative Care Strategy (the Strategy) was developed in 2018 in response to an evaluation of the previous 2010 national strategy. It sets a vision for Australia that: (7)

> *"People affected by life-limiting illness get the care they need to live well."*
>
> National Palliative Care Strategy 2018

It recognises that people who require palliative care may be at different stages of their illness trajectory and may need palliative care for a short period of time, intermittently, or consistently over a period of months or years.

The Strategy also notes the diversity in those requiring palliative care, including that they may be young or old, and have different cultural, social, emotional, relational and spiritual needs. It sets out a range of initiatives to strengthen palliative care against seven goals: (7)

- **Understanding:** The public should understand the benefits of palliative care and know how to access services, and are involved in decisions about their own care
- **Capability:** Knowledge and practices of palliative care is embedded in all care settings
- **Access and Choice**: People affected by life-limiting illnesses receive care that matches their needs and preferences
- **Collaboration:** Everyone works together to create a consistent experience
- **Investment:** A skilled workforce and systems are in place to deliver palliative care in any setting
- **Data and evidence:** Robust national data and a string research agenda strengthen and improve palliative care
- **Accountability:** National governance of this Strategy drives action.

As a result of the Strategy, several palliative care programs have been implemented by the Commonwealth including, but not limited to, the Greater Choice for At Home Palliative Care Program and the Comprehensive Palliative Care in Aged Care Measure.

The Greater Choice for At Home Palliative Care program

The Australian Department of Health, Disability and Ageing's *Greater Choice for At Home Palliative Care Program* is a national initiative designed to improve the coordination and delivery of palliative care services for people who wish to be cared for and die at home. The program recognises the palliative care preference for many Australians and aims to make it a reality.

The key objectives of the program are to: (8)

- improve access to quality palliative care at home
- enhance care coordination
- reduce unnecessary hospitalisations
- utilise technology
- support consumers and their families.

The PHN has been participating in the program since 2021, and this Report will be used to help inform delivery in the North Brisbane and Moreton Bay region through to 2029.

Queensland Palliative Care Strategy, 2022

The Queensland Government's Palliative and End-of-Life Care Strategy (the Queensland Strategy) was released in 2022, and was supported by approximately $171 million in additional government investment from 2021-22 to 2025-26. The Queensland Strategy has set a vision to ensure all *Queenslanders with a life-limiting illness and their families receive equitable, compassionate, and high-quality palliative care that aligns with their individual needs, preferences and goals at the end of life*. The Queensland Strategy focuses on critical areas to achieve this goal: enhancing access to quality services (especially in regional, rural, and remote areas), promoting informed choice about care and place of death, and ensuring care is person-centred and respectful of culture and identity.

To deliver this, the Strategy includes 44 specific actions across seven goals, emphasising a strong focus on strengthening the workforce and community supports. Key initiatives include a major investment to grow Queensland Health's specialist palliative care workforce, expanding and funding community-based services to support care at home, enhancing digital and telehealth solutions for better access and consultation including 24 hours a day, and providing education for the public and professionals on end-of-life care and advance care planning.

Voluntary Assisted Dying (VAD)

While it is acknowledged that the hastening of death is not part of the palliative care definition, for the purpose of this Report the consumer needs, barriers and services provided to support VAD have been included in the Report in order to reflect all services available to consumers at an end-of-life stage in Queensland.

The *Voluntary Assisted Dying Act 2021 (Qld)* was passed in September 2021 (commencing in January 2023). (9)

There are explicit restrictions surrounding situations when VAD can be discussed and where health professionals can engage in these discussions and provide information. In Queensland, a medical practitioner or nurse practitioner can initiate and engage in VAD discussions but must also provide information regarding alternative options including palliative care however still have obligations to refer a consumer to a non-objecting professional if approached. Service organisations who select not to participate also have an obligation to ensure their consumers can access VAD through an alternative pathway if requested. (10)

The criteria surrounding which medical conditions are eligible for VAD mean that some conditions are excluded. The condition must be advanced, progressive and expected to cause death. A disability or mental illness alone is not sufficient to qualify for VAD. It is important to note that generally people with dementia cannot access VAD because by the time their dementia is advanced enough to qualify for VAD, they have typically lost capacity and are unable to make decisions regarding their medical care. (10)

Additionally, children and younger persons below 18 years of age with palliative needs are unable to access VAD, with no exceptions. The typical Gillick competency that applies to 16 and 17 year olds which allows mature children to have autonomy over their own medical decisions does not apply to VAD. (11)

Scope and limitations

The scope of the Report includes:

- the mainland areas serviced by the PHN (defined further in Part 2 of this Report – excluding Norfolk Island)
- all adults and children residing in the North Brisbane and Moreton Bay region and accessing palliative care across primary care, community and hospital and health services
- all public and private palliative care related services delivered in the region- this includes generalist service providers such as GPs and pharmacists who provide palliative care as part of their role, as well as specialist palliative care providers who exclusively provide palliative and end-of-life care (such as Hummingbird House and Karuna Hospice Services).

Importantly the Report reflects a point in time analysis, drawing on the needs and services in the North Brisbane and Moreton Bay region as at November 2025.

Public data and information sources that have been used to inform the findings in this Report have been noted. Where possible, stakeholder insights have been used to help support quantitative and research-based findings.

It is noted that there is very limited data available about palliative care services and consumer needs specific to the Brisbane North PHN region. Where possible relevant data has been included, or has been provided at a Queensland or national level. Future collection of data and information specific to palliative care services within the region will help to provide a more robust assessment of services and needs.

Report structure

This Report details the findings against the following key sections, which seek to answer key areas of inquiry:

- **Introduction:** Including defining palliative care and the method and scope of this Palliative Care Needs Assessment
- **Part 1:** Prevalence and demographics of palliative care across the region
- **Part 2:** Current Palliative care services in the region
- **Part 3:** Needs and circumstances of those requiring palliative care

- **Part 4:** Healthcare supply and service provider barriers
- **Part 5:** Health service utilisation and consumer barriers
- **Conclusion:** Including high level recommendations to support palliative care needs across the region into the future.

It is noted that there are parts of the Report which align with more than one section, for example discussion on social isolation, which can be viewed as parts of the consumer needs and circumstances of the population, as well as a consumer barrier to accessing appropriate care.

Process

The Report has been developed using four key phases to inform the findings as outlined below.

1. Desktop review

A detailed desktop review was undertaken. This included analysis of data provided by the PHN from the Joint Regional Needs Assessment and palliative care information. Publicly available contemporary research and policy on palliative care, including emerging priorities, was also reviewed. This review established a foundational understanding of the current state of palliative care across the region. All information sources have been identified in the reference list.

2. Service provider interviews

Individual interviews with 20 palliative care service providers across the North Brisbane and Moreton Bay region were undertaken. These explored palliative care needs, priorities, barriers and service gaps from the service provider perspective. The identification of these service providers has been undertaken in collaboration with Brisbane North PHN. A full list of stakeholders consulted, including these service providers, is included in Appendix A.

3. Consumer, carer and advocacy focus groups

Three focus groups were undertaken with approximately 40 people to reflect the views of consumers, families and carers and advocacy groups from across the region. The six individual consumers and carers consulted as part of this process will not be publicly listed, however peak bodies consulted as part of engagement are included in Appendix A (without listing the names of each representative).

4. Final report and recommendations

A final needs assessment was developed in the form of this Report. The findings in this Report are based on both quantitative and qualitative insights gained throughout the engagement process. All findings were verified through a validation survey sent out to each stakeholder involved in the consultation phases to ensure that the findings accurately reflected the combined perspectives of stakeholders in the region.

Part 1. Prevalence and demographics of palliative care in Brisbane's north

This section describes the current prevalence of palliative and end-of-life care needs across the PHN's region, including differences in demography (by age and gender), geography (described by Statistical Area 3), leading health causes and nuanced findings for key priority population cohorts.

1.1 Geography

The geographical catchment captured by the PHN is located north of the Brisbane River and includes Brisbane's northern suburbs, Moreton Bay Regional Council and parts of the Somerset Regional Council. Whilst the PHN also supports Norfolk Island, it is not considered in this Report. This geographical area of the PHN spans approximately 4,100 square kilometres covering a largely urban footprint.

This region comprises five subregions: Redcliffe-North Lakes, Pine Rivers, Brisbane Inner City, Brisbane West, Moreton Bay – North and Brisbane North. Across these regions, there are a total of 19 Statistical Area 3 (SA3) regions which are listed in Table 1.

1.2 Demography

As of 30 June 2023, the North Brisbane and Moreton Bay region estimated residential population was 1,117,678 persons. This region is projected to increase by approximately 30 per cent to 1,452,296 by 2036 (not including Norfolk Island). (12)

The 19 SA3 areas have varying population sizes which are all expected to continue to grow as shown in Table 1. The more urban locations such as Brisbane Inner and Brisbane Inner-North have the largest populations, while Caboolture Hinterland is significantly smaller. By 2036, it is noted that the largest populations are predicted in Brisbane Inner, Narangba-Burpengary and North Lakes showing population growth will vary across each SA3 region. These changes in population size and demography will impact on the demand for palliative care services over time, particularly given this is an area where services are likely to be sought where possible close to a person's home.

The Brisbane North PHN region has a socio-economic indexes for areas (SEIFA) of relative socio-economic disadvantage of 1,029 compared to national score of 1,000. This indicates a higher level of socio-economic advantage overall than the national average. (13) However, there is also significant variations between SA3 areas within

Table 1: Key demographic and economic indicators (13)

Subregion	SA3	Estimated resident population (2023) (12)	Projected population by 2036 (12)	Life Expectancy (2023) (14)	Number of deaths in 2023 (100)	Age standardised rate (deaths per 100,000) 2023 (100)	SEIFA IRSD (12)
Redcliffe – North Lakes	Redcliffe	65,627	85,569	81.5	747	591.3	965
	North Lakes	93,051	126,320	84.6	453	549.2	1011
Pine Rivers	Strathpine	41,068	54,226	84.6	242	551.4	976
	The Hills District	92,325	102,043	84.6	338	348.1	1086
Brisbane Inner City	Brisbane Inner	93,635	148,372	84.6	348	458.2	1039
	Brisbane Inner – North	104,070	124,668	84.6	478	471.9	1077
	Brisbane Inner - West	62,071	70,925	84.6	184	327.8	1098
Brisbane West	Kenmore – Brookfield – Moggill	48,576	48,927	85.6	273	359.0	1105
	Sherwood – Indooroopilly	56,034	62,333	85.6	224	346.9	1069
	The Gap – Enoggera	55,434	58,513	85.6	350	492.6	1066
Moreton Bay North	Bribie – Beachmere	38,483	42,212	81.5	456	436.4	958
	Caboolture	84,582	125,970	81.5	731	720.3	921
	Caboolture Hinterland	15,536	20,305	81.5	103	547.6	974
	Narangba – Burpengary	72,334	127,148	81.5	477	564.3	980
Brisbane North	Bald Hills – Everton Park	47,708	52,737	82.7	330	476.3	1072
	Chermside	76,165	81,781	82.7	621	538.2	1046
	Nundah	44,460	56,233	82.7	276	549.9	1043
	Sandgate	62,463	65,014	82.7	477	552.5	1006

the north Brisbane area, with Caboolture, Bribie-Beachmere, Strathpine and Redcliffe exhibiting more socio-economic disadvantage and Kenmore-Brookfield- Moggill and Brisbane-Inner West indicate higher relative advantage.

For the population across the region, children (aged 0-14 years) represent 17.4 per cent of the population and older persons (65 years and above) represent 15.5 per cent of the population. (14) As per Table 2, in 2022, Brisbane North PHN had the third largest population aged 65 and above when compared to other PHN's across Queensland, at 168,010 people. There has been significant growth in the ageing population in PHN increasing by 24.5 per cent from 2016 to 2022. This significant ageing population, in addition to population growth are expected to increase the demand for palliative and end-of-life care services over the coming decade. (5)

Table 2: Population aged 65 years and above by PHN, Queensland (5)

Primary Health Network	Population aged 65 and above, 2022
Brisbane North	168,010
Brisbane South	175,340
Central Queensland, Wide Bay, Sunshine Coast	206,480
Darling Downs and West Moreton	104,660
Gold Coast	117,200
Northern Queensland	116,190
Western Queensland	8,940

As per Table 3, 82 per cent of deaths in 2023 in the state were people aged 65 years or more indicating a significant need for palliative care across the elderly population. However, there is still a number of deaths across all age groups from infants all the way up to 64 years and thus a need for palliative care across all age cohorts. (15)

Table 3: Number of deaths by age group in Queensland, 2014 and 2023 (15)

Age	Deaths in 2014	Deaths in 2023
Under 1 year	273	277
1-14	101	115
15-24	251	273
25-34	414	449
35-44	709	778
45-54	1,396	1,547
55-64	2,786	3,236
65-74	4,799	6,136
75-84	7,436	10,538
85+	10,608	13,792
Total	28,773	37,141

Table 4 shows that the population within the PHN catchment is ageing over time, with 19 per cent of those aged 65 years and older in the population expected by 2036, compared with 17 per cent in 2026. In addition, the over 80 years cohort will grow by 5.1 per cent annually, much faster than any other age cohort. This increase in the proportion of the population who are over 80 years across the region will further increase the demand for palliative care and end-of-life services over time. Analysis at the SA3 level shows that the areas with the highest ageing populations are in Bribie-Beachmere, Redcliffe and Caboolture-Hinterland. (16)

Table 4: The PHN- projected population, by five–year age group, 2026 to 2036 (17) (18)

Age	Estimated Population 2026	Estimated Population 2036	Annual Growth Rate
0-9	126,607	137,486	0.8%
10-19	147,354	148,819	0.1%
20-29	169,013	205,891	2.0%
30-39	170,483	188,764	1.0%
40-49	159,141	182,578	1.4%
50-59	141,953	160,407	1.2%
60-69	114,483	135,216	1.7%
70-79	89,344	108,808	2.0%
80+	52,833	86,425	5.0%
Total	**1,171,213**	**1,354,393**	**1.5%**

Key Finding 1: The North Brisbane and Moreton Bay region has a population that is both growing and ageing, which will drive a significant increase in the demand for palliative and end-of-life care over the next decade. While demand will grow across the entire region, it is expected to significantly increase in the urban fringe including the North Lakes, Caboolture, and Narangba – Burpengary areas.

The population residing within the PHN catchment is expected to grow by around 30 percent to 2036, but its growth will be uneven, with significant growth towards the outer urban fringe of North Lakes and Narangba-Burpengary. The population residing within the PHN catchment is expected to grow by around 30 per cent to 2036, but its growth will be uneven, with significant growth towards the outer urban fringe of North Lakes and Narangba-Burpengary.

While palliative care impacts all ages, there is significantly higher rate of palliative and end-of-life care needs from 55 years and over, increasing in prevalence again at over 75 years of age. The ageing of the population also varies across the region, with older population cohorts as a proportion of the population across the Bribie-Beachmere, Redcliffe and Caboolture Hinterland regions.

1.3 Leading causes

It is important to recognise that not all deaths require, or are appropriate for, palliative and end-of-life care. While many people who die from progressive, life-limiting illnesses benefit from palliative approaches, others may experience sudden or unexpected deaths where such care is not relevant or feasible. Understanding the leading causes of death within this context is therefore essential. Mortality data can provide valuable insights into population health and potential palliative care demand, but it must be interpreted with nuance—acknowledging that the need for palliative care varies according to disease trajectory, timing of diagnosis, and individual circumstances.

The need for palliative care in Australia is strongly driven by the ageing population and high prevalence of chronic, progressive diseases. In 2022, chronic conditions were recorded as an underlying or associated cause of death for 171,500 people, representing 90 per cent of all deaths, or a rate of 659 per 100,000 persons. (19)

Estimates suggest that 50–90 per cent of people who die each year could benefit from palliative care, with conservative figures indicating this includes around 80,000 Australians annually. (7) Demand for palliative care is projected to increase over time due to an ageing population, rising rates of multi-morbidity, and the growing prevalence of chronic progressive illnesses with a high symptom burden. (6) This highlights the need for proactive planning and investment in palliative care to meet the needs of an increasingly complex population.

The North Brisbane and Moreton Bay region has a higher than average general level of health. The regions with the highest identified health needs include Bribie-Beachmere, Caboolture, Narangba-Burpengary, Redcliffe and Sandgate. (14)

The leading causes of avoidable mortality vary between females and males as per Table 5. However, cancer, coronary heart disease and stroke are leading causes of avoidable mortality across the entire population.

Table 5: Leading causes of avoidable mortality, Brisbane North PHN region 2018-2022, by gender (20)

Causes of death in females		**Causes of death in males**	
Condition	**ASR**	**Condition**	**ASR**
Dementia	52.53	Coronary heart disease	69.28
Coronary heart disease	37.64	Dementia	43.36
Cerebrovascular disease (stroke)	29.61	Lung cancer	34.22
Lung cancer	21.56	Cerebrovascular disease (stroke)	29.61
Breast cancer	17.77	Prostate cancer	26.73

1.4 Priority populations

Research suggests that there are very specific palliative care needs and requirements for priority population cohorts. While this report seeks to draw out some of the specific considerations for priority cohort groups, it is noted that there is often intersection between these cohorts (for example where a person identifies as both Aboriginal and LGBTIQA+). In addition, needs and preferences within priority cohort groups are not homogenous, requiring individual needs and preferences to be reflected and considered in palliative and end-of-life care.

Where individuals may experience an intersection across priority cohorts, this may lead to compounding disadvantage. For every individual, the nuance of their unique needs and identity must be considered within the context of their disadvantage and potential complexity surrounding their own vulnerability.

Key Finding 2: The leading causes of death requiring palliative care for people living in the region is varied, and includes cancer, coronary heart disease, cerebrovascular diseases (stroke), dementia and respiratory disease. There are some differences in palliative care needs by gender, with breast cancer a leading cause of death for females and prostate cancer for males. Dementia is the leading cause of death for females and second leading cause of death for males in the region, and is often overlooked in palliative care.

Coronary heart disease and dementia are the leading causes of death across males and females in the region, but there remain differences in the health cause of death across the region based on gender.

These differences in the health causes of palliative care across the region are important to understand as while the principles of palliative and end-of-life care are similar regardless of the cause, the specific needs, symptoms and care pathways can vary significantly depending on the health cause of death.

Key Finding 3: While the majority of persons requiring palliative and end-of-life care are older (approximately 60 percent are over 65 years), there is a need for palliative care services across all age cohorts.

Key Finding 3: While the majority of persons requiring palliative and end-of-life care are older (approximately 60 per cent are over 65 years), there is a need for palliative care services across all age cohorts.

When experiencing death and dying, it is crucial for every individual's preference to be accounted for and assumptions and generalisations surrounding how they would like to receive palliative care should be avoided.

> *"It is important with every single patient that we don't generalise. We don't make assumptions" – Palliative Care Service Provider*

Table 6 provides estimations of the population size of key priority cohort groups within the North Brisbane and Moreton Bay region.

Table 6: Estimated population for priority cohort groups within the PHN region

	2021 ERP Population	**Proportional growth to 2036****
Aboriginal and Torres Strait Islander people (21)	32,373	42,065
People from culturally and linguistically diverse backgrounds (13)	257,220	334,228
People who identify as LGBTIQA+* (22)	41,242	53,589
People with disability	58,442	75,939
Homeless people (12)	3,596	4,673
People with dementia (23)	15,595	20,264

**Note: This estimate is based on applying the estimated national percentage of people identifying as LGBTIQA+ to the PHN population.*

*** This estimates the 2036 population by applying the same proportional growth to the overall population. This will therefore not account for growth where growth in the priority cohort exceeds population growth, such as for homelessness and those in at risk housing, and for First Nations populations.*

1.4.1 Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander people make up 2.5 per cent of the population of the North Brisbane and Moreton Bay region. The SA3 regions with highest First Nation populations are Caboolture (6.5 per cent), Narangba-Burpengary (4.7 per cent), Strathpine (4.5 per cent), Caboolture Hinterland (4.4 per cent), and Redcliffe (3.8 per cent). (20) (24) The age group with the highest proportion of Aboriginal and Torres Strait Islander population are aged between 0 and 4 years, reflecting high birth rates. (14)

Aboriginal and Torres Strait Islander people living in the region also have double the rate of cancer incidence relative to Queensland and the 5-year survival rates following cancer are 24 per cent lower. (14) Specifically, Aboriginal and Torres Strait Islander people have a higher incidence rate and mortality rate and lower 5-year survival rate for lung cancer, breast cancer for women, liver cancer and pancreatic cancer. (14) The highest areas of need for First Nations people based on cancer incidence in the region were in Kilcoy, Caboolture, Brisbane City, Pine Rivers, and Redcliffe. (14)

Nationally, Aboriginal and Torres Strait Islander people experience a burden of disease 2.3 times the rate of non-Indigenous Australians. In Queensland in 2023, the leading causes of death in Aboriginal and Torres Straits Islanders were: (25)

- ischaemic heart disease (131 per 100,000)
- lung cancer (87 per 100,000)
- diabetes (86 per 100,000)
- respiratory diseases (73 per 100,000)
- self-harm (69 per 100,000).

While not all of these causes of death require palliative and end-of-life care, the differences in health conditions and prevalence compared with the general population (such as respiratory disease) need to be considered to ensure a nuanced understanding of palliative needs across for First Nations people in the region.

Despite palliative care-related hospitalisation rates being nearly twice as high amongst Aboriginal and Torres Strait Islander people, only 1.3 per cent of palliative care encounters in general practice are provided to Aboriginal and Torres Strait Islander peoples highlighting under-representation in community care. With the Aboriginal and Torres Strait Islander elder population in Brisbane North projected to grow by 34 per cent over the next five years, there is a critical need for culturally safe, trauma-informed, and community-aligned models of palliative and aged care. (14)

1.4.2 People from culturally and linguistically diverse backgrounds

When discussing people from culturally and linguistically diverse backgrounds, it is important to remember this is not a homogenous group and there are a vast number of different cultures and ethnic backgrounds within this group. Each distinct cultural and spiritual group must be treated with specific consideration of their own individual needs and beliefs.

In 2023, 14.3 per cent of the Brisbane North PHN population identified as coming from non-English speaking backgrounds. (14) The most common languages spoken include Chinese, Indo-Aryan, Spanish and Portuguese, Southeast Asian, Indian and Italian. (26)

In the period 2016-17 to 2019-20 in Queensland, individuals who were born in Tonga, Serbia, Ukraine, Cook Islands and Poland had death rates that were significantly higher than the Australian born population. (27)

People from culturally and linguistically diverse backgrounds in general experience higher socio-economic disadvantage and higher self-reported impacts of physical body pain. (28) The leading causes of death for people from culturally and linguistically diverse backgrounds are similar to that of the general Queensland population including ischaemic heart disease, dementia, stroke, cancer and respiratory disease. Additional comorbidities and health needs for residents from culturally and linguistically diverse backgrounds vary, with mental health, dementia, heart disease, pain, oral health and diabetes as key needs identified. (14)

1.4.3 Refugees

Australia has a significant refugee population that must also be considered in the context of palliative and end-of-life care. Since World War II, Australia has welcomed nearly one million refugees. (29) The all-cause mortality rate for humanitarian entrants to Australia from 2007-2020 was 310 deaths per 100,00 person years which is notably higher than other permanent migrants. The leading causes of death are similar to that of the Australian population including coronary heart disease, lung and breast cancer, stroke and dementia. (30)

In Queensland, there have been 23,977 permanent humanitarian settlers in the ten years between July 2015 and June 2025. Information is provided by Local Government Area (LGA) for refugee settlement, and for the three LGAs that are primarily within the PHN catchment (i.e., Brisbane, Moreton Bay, Somerset), there were 7,363 humanitarian settlers over the 10-year period to June 2025. (31)

1.4.4 People who identify as LGBTIQA+

It is estimated that 3.9 per cent of the Queensland population over the age of 16 identifies as LGBTQIA+. (22) Included within this cohort are the 0.95 per cent of the Queensland population over 16 years old, and 0.87 per cent of the Australian population, that report a gender that is different to that recorded at birth (trans and diverse). (22)

Recent studies have highlighted that people who identify as LGBTIQA+ have higher rates of stroke and heart disease than the general population. (32) This is consistent with growing evidence that this population experience increased prevalence of several cardiovascular risk factors such as tobacco use, elevated body mass index and diabetes. (33) It has been suggested that these risk factors in combination with the increased level of stigma and discrimination that this cohort often experiences leads to an increased disease burden. (33)

Additionally, this cohort experience higher rates of cognitive impairment, including dementia. This is reported to be due to the interplay of social disadvantage and various risk factors such as: poorer mental and physical health, elevated stress and social isolation. (34)

1.4.5 People with disability

The Joint Regional Needs Assessment in 2024 identified that 5.5 per cent of the residents of the Brisbane North PHN catchment have a severe or profound disability. (14)

In 2024, NDIS participants in the North Brisbane and Moreton Bay region totalled 27,020, with the highest proportion residing in the SA3 regions of Caboolture, North Lakes, Narangba-Burpengary, Redcliffe and The Hills District. (20) The SA3 regions with the highest number of carers to people living with a disability, older person, or person living with a health condition in 2021 were residing in the Hills District, Caboolture, Brisbane Inner North, North Lakes and Redcliffe. (20)

It is also important to note that there is a higher prevalence of disability amongst the First Nations people in this region, where 8.6 per cent of those under 65 years and 29.8 per cent of those over 65 years have a profound or severe disability. (21)

Nationally, people with disability who use disability services have a mortality rate that is 4.7 times higher than the general population. (35) The leading causes of death are distinct from that of the general population, with most common underlying causes of death for this cohort being respiratory diseases including pneumonia, nervous systems diseases including epilepsy, circulatory diseases including ischaemic heart disease, and cancer. (36)

1.4.6 Those with neurodegenerative conditions including people with dementia

There are unique needs around end-of-life care and choice and control available to the consumer for those with a neurodegenerative health disease. This can create additional challenges around supporting consumer choice and control. These include, but are not limited to, progressive neurodegenerative diseases such as Alzheimer’s Deases and Vascular Dementia, Parkinson’s Disease and neurological diseases such as Multiple Sclerosis and HIV-associated neurocognitive disorders.

Of these, dementia is one of the leading causes of death and is increasingly recognised as a terminal condition for which palliative care is appropriate. In 2025, there are estimated to be 29,000

Australians with early onset dementia (30–50-year-olds). (37) In 2023, one in six deaths in Australia were associated with dementia. (23) Two in three people with dementia in Australia are believed to live in community. (37) Of those in residential aged care homes in Australia, 54 per cent have dementia. (37)

Considerations for managing choice and control for these consumers include understanding that cognitive capacity may be decision-specific (for example lacking the capacity to consent to a major medical procedure but be able to make other decisions such as what to eat) and be time bound, noting capacity must be assessed at the time of the decision. The establishment of advanced care planning is also important to assist in understanding and documenting consumer preferences and choices. Further information on specific needs is included in Part 3 of this Report.

1.4.7 Homelessness and those in at risk housing

The Brisbane North PHN Homelessness Needs Assessment 2025, found that homelessness is increasing across the region, with large number of people seeking Specialist Homelessness Services. Stakeholders also noted increased rates of all types of homelessness across the region. (12) The spread of homelessness is varied occurring in both inner-city areas of Brisbane as well as metropolitan outer suburbs such as: Caboolture and Redcliffe. It is noted that the Homelessness Health Needs Assessment Report identified that that available data is likely to under-report current rates of homelessness and those in at risk housing across the region. (12)

Those experiencing homelessness within the North Brisbane and Moreton Bay region are more likely to have a long-term health condition which may require palliative care. In particular, there is an increased prevalence of heart disease with 15 per cent of respondents in a survey conducted by Brisbane Zero reporting a type of heart disease amongst the homeless population compared to the national average of 5.2 per cent. Additionally, there is a higher prevalence of kidney disease (9 per cent compared with 1 per cent nationally) and hepatitis C (18 per cent versus 0.78 per cent nationally). (12)

Aboriginal and/or Torres Straits Islanders are more likely to be living in overcrowded places and represent 10.7 per cent of homelessness within the North Brisbane and Moreton Bay region. (12) The SA3 regions with the highest per centage of Aboriginal and/or Torres Strait Islanders in overcrowded housing are Caboolture (14.8 per cent), Narangba- Burpengary (14.2 per cent), Caboolture Hinterland (12.9 per cent), Sandgate (12.9 per cent) and Strathpine (12.0 per cent). (20)

1.4.8 Younger persons with palliative care needs

Younger persons can often be overlooked when considering palliative care needs due to the stereotypes and perception of palliative care. However, youth continue to face the challenges of disability, death and life-limiting illness. (1) Leading causes of death requiring palliative care are different for children and youth compared with the general population, and also differ by age range. These causes include perinatal and congenital conditions, brain cancer and selected metabolic disorders. (38)

In Australia in 2020, most children who died were aged 1- 4 years old (12.8 per 100,000 children). (39) The Australian rate of child deaths was found to be more than double in lower socio-economic areas (12.3 per 100,000 compared to 5.4 for higher socio-economic areas). (39) These rates also increased in more remote locations with a rate of 15.7 per 100,000 children aged 1-14 years in very remote areas compared to 7.3 for metro regions. Neonate and child mortality is a key focus within the PHN region, and is partially attributed to high rates of obesity and smoking during pregnancy. (14)

As of May 2025, Children's Health Queensland were engaged with 74 children via their Specialist Palliative Care Service within the Brisbane North PHN region. Of these, 12.4 per cent identified as First Nations whilst 2.9 per cent were of a culturally and linguistically diverse background and required an interpreter. (40)

In 2018, an average of 4.5 per cent of children in Australia between ages 0-14 had a severe or profound disability requiring assistance and care. This increased to 11 per cent for Aboriginal and/or Torres Strait Islander children. (39) Consideration needs to be given to the intersection between children requiring palliative care and those with a disability which are likely to increase complexity in the models of care and supports required.

In 2020, children aged 0-14 had a cancer age specific death rate of 1.8 per 100 000 cases. However, the five-year survival rate for all cancers among children aged 0-14 has increased over time, from 73.1 per cent in 1988-1992 to 85.4 per cent in 2013-2017. (39)

1.4.9 Stolen Generation, Care Leavers and Forgotten Australians

It is estimated that 500,000 children were placed in institutional care in Australia between the 1920s and the 1980s, known as Forgotten Australians. Many were subject to neglect and isolation. (41)

In addition, whilst it is difficult to obtain exact figures, it is approximated that:

- between 1910-1970, 25,000 Aboriginal and Torres Strait Islander children were forcibly removed from their family, known as the Stolen Generation
- in the 20th century, 6,000-7,500 children were sent to Australia as child migrants from the United Kingdom and Malta.

It is not possible to enumerate the exact figures for the number of people affected by forced adoptions, however tens of thousands of people have been impacted and this impact continues across generations. (42)

There is a significant lack of literature on this specific population, however there is some evidence indicating higher rates of chronic health conditions, history of abuse, drug and alcohol misuse and mental health issues such as post-traumatic stress disorder, abandonment, depression and anxiety. (42)

Specifically, the stolen generation experience higher prevalence of long-term health conditions and poorer health outcomes. (43) There is a higher incidence of cancer, kidney disease, Chronic Obstructive Pulmonary Disease (COPD) and hypertension amongst the Stolen Generation population aged 50 and over when compared to an Indigenous reference group. (43)

Trauma-informed approaches are also critical to addressing the health needs for this cohort due to the institutionalisation of this cohort and distrust in the system, particularly government and faith-based organisations. (42)

1.4.10 People who are incarcerated

There are two primary prison locations in the PHN catchment with a rapidly growing population in both locations:

- Helena Jones Centre, Albion – 22 bed low security women's prison (44)
- Woodford Correctional Centre – high security male's prison. (45)

Woodford Prison as of 15 August 2023 had 1,506 prisoners with a built bed capacity of 1,638. (46) The Woodford Prison population continues to grow over time with 1,109 prisoners in 2015/16, increasing to 1,391 in 2018/19. (47)

Nationally, not only is the total number of prisoners growing, but the proportion of older prisoners continues to rise, attributed to longer sentences and reduced options for early release. (48) The demographic profile of Australia's prison population is characterised by primarily young adult males from lower socioeconomic backgrounds with a history of trauma. National data suggests: (48)

- 29 per cent of prison entrants in Australia report a long-term health condition or disability whilst 30 per cent report a chronic condition
- one in three were homeless in the month prior to entering prison
- 40 per cent report a mental health diagnosis at some point in their lives
- 66 per cent report illicit drug use in the year prior to entering prison.

It is important to note that Aboriginal and Torres Strait Islanders and adults with intellectual disabilities are overrepresented within the prison population. (48)

In Australia from 2000 to 2022, 65 per cent of deaths in prison can be attributed to natural causes, such as ageing. (49) The number of people aged 45 years or above in Australian prisons has increased to 23 per cent from 2012 to 2022 and this is rising disproportionately to other groups. (50) The ageing prison population in combination with a high rate of social disadvantage leads to a high burden of chronic disease and need for increased healthcare support and often palliative care. There is a lack of reliable data on palliative care needs within prisons across Australia. (50)

1.4.11 Veterans

As of June 2025, there were 97,311 veterans (and dependents) entitled to medical and other treatment under the Department of Veteran's Affairs (DVA) expense in Queensland (78.2 per cent male, to 21.8 per cent female). (51) The majority of veterans in Queensland are aged between 70 and 79 years (19.5 per cent). (51) Within the LGAs that are primarily within the PHN's catchment (i.e., Brisbane, Moreton Bay, Somerset), there are 36,594 DVA clients (of which 29,942 are veterans) as at October 2025. (51)

The leading causes of death among male veterans includes land transport accidents, suicide and coronary heart disease, whilst for females the leading causes are suicide, breast cancer and lung cancer. (52) This is quite distinct to the general population, and the added prevalence of Post-Traumatic Stress Disorder (PTSD) has implications for palliative care as an exacerbation of PTSD symptoms is an identified phenomena in palliative patients. (51)

Key Finding 4: Some priority cohort groups have differences in the health causes of palliative and end of-life care - including First Nations Australians, people with disability and veterans compared with the general population. Some priority groups face significant complexity due to wider social determinants that may impact their palliative and end-of-life care needs, for example those who are incarcerated and those experiencing, or at risk of, homelessness.

Palliative and end-of-life prevalence varies across priority cohort groups (noting further discussion on needs is in Part 2 of this Report). This includes:

- *First Nations Australians*. The leading causes of death are ischaemic heart disease, lung cancer, diabetes and respiratory disease. In addition, rates of cancer are double that of all Australians, and the overall health burden is 2.3 times higher than the general population. This cohort are also more likely to face complexity due to disadvantage in relation to the social determinants of health.
- *People from culturally and linguistically diverse background*. The leading causes of death are similar to the mainstream population but persons from culturally and linguistically diverse backgrounds generally experience higher socio-economic disadvantage and higher self-reported impacts of physical body pain and existing trauma.
- *Refugees.* The leading causes of death are similar for refugees to the general population, but the mortality rate is much higher.
- *Those who identify as LGBTIQA+.* There are higher rates of stroke, heart disease and dementia than the general population, and this cohort is also more likely to experience complexity due to higher rates of mental ill health, and social isolation.
- *Those with a disability.* This cohort experience different leading causes of death to the general population, and this includes respiratory diseases including pneumonia, nervous systems diseases including epilepsy, circulatory diseases including ischaemic heart disease and cancer.
- *Those who are cognitively impaired due to a degenerative health condition.* This group have been identified because consumer choice and control can be impacted by cognitive impairment towards the end-of-life and, while this may be due to a number of degenerative diseases, dementia remains one of the leading causes of death for both females and males in the region.
- *Those who are homeless or in at risk housing.* This group are more likely to have heart disease, kidney disease and Hepatitis C than the general population, and experience complexity due to wider social determinants, including socio-economic disadvantage, higher rates of mental ill health and substance misuse, and higher rates of chronic disease and trauma.
- *Younger persons.* Children and youth have differing health causes of palliative and end-of-life care than the general population including but not limited to perinatal and congenital conditions, brain cancer and selected metabolic disorders.
- *Stolen Generation and Care Leavers.* Information on this cohort and leading causes of death is limited, however there is higher incidence of cancer, kidney disease, COPD and hypertension amongst the stolen generation population aged 50 and over when compared to an Indigenous reference group.
- *People who are incarcerated.* Wider socio-economic disadvantage and social determinants may impact on the palliative and end-of-life needs of those who are incarcerated, including mental ill health, previous substance misuse and existing long term health conditions.
- *Veterans.* The leading cause of death requiring palliative and end-of-life care are different for this cohort than the general population and for males includes coronary heart disease whilst for females leading causes include breast cancer and lung cancer. The high prevalence of PTSD has implications for palliative care.

Part 2. Palliative care services in the region

This section details the key settings in which palliative and end-of-life care are provided across the North Brisbane and Moreton Bay region, as well as some discussion in relation to consumer preferences in relation to the setting in which they receive palliative and end-of-life care.

2.1 Home based care

Most Australians prefer to receive care at home at the end-of-life, with around 90 per cent wanting home-based care and 50 per cent expressing a preference to die at home. (53) Despite this, only as few as five per cent actually die at home, highlighting a persistent gap between patient preferences and service delivery. The rates of dying at home are lower in Queensland, at only two per cent in analysis undertaken by the Australian Bureau of Statistics (ABS) in 2021. (54) Some service providers reported they believe the dying at home rate in the region is higher than the Queensland rate of two per cent reported by the ABS in 2021, but further data collection is needed to quantify this rate for the region.

Across the PHN catchment, the median length of stay prior to death for home-based recipients of palliative care is 16.1 months compared to the national average of 16.6 months. (55) Early identification and proactive management within the home could substantially increase the proportion of residents supported to die at home, while also reducing avoidable hospitalisations.

There are three specialist palliative care services supporting home-based specialist palliative care for adults in the North Brisbane and Moreton Bay region:

- Metro North Health Community Palliative Care
- Karuna Hospice Services
- St Vincent's Private Hospital Community Specialist Palliative Care Service.

Access to primary care palliative services is widely recognised as key to enabling home-based care. However, workforce and funding constraints limit available service provision. This is discussed further in section 4 of this Report.

> *"As far as people being able to die at home, we need more people on the ground who can help people stay at home. This might include Nurse Practitioners and Registered Nurses who can support the end-of-life stage and who are able to provide breakthrough pain relief." –*
> *Palliative Care Service Provider*

New initiatives, such as the End-of-Life Pathway for aged care participants at home (Support at Home program), aim to improve early diagnosis, care planning and timely clinical support within the community. Recommendations from Palliative Care Australia to improve home-based access include quarterly payments for primary care practices and expanded use of Medicare Benefits Schedule (MBS) items to support sustainable, high-quality home-based palliative care. (53)

One service provider noted that there are some funeral providers on Brisbane's northside who are exploring providing a space for people to die with their loved ones in order to provide an alternative option to dying at home where it is safe to do so.

2.2 Residential aged care homes

A large proportion of older Australians spend their final years within a RACH. There are currently 87 RACH in the Brisbane North PHN region, making up 19 per cent of RACH across the state. When compared to the number of RACH in other PHNs, Brisbane North is significantly above the average of 65 RACH per PHN, and only Brisbane South PHN (93 RACH) and Central Queensland PHN (97 RACH) had a higher number. (56) In Queensland, 41.2 per 1,000 people aged 65 and over, utilise permanent residential care.

Nationally, around 30 per cent of all deaths occur in RACHs, rising to 50 per cent among people aged 85 years and older. (53) The average resident dies within two years of admission, typically from a life-limiting illness, highlighting the importance of embedding palliative approaches into routine aged care practice. In Brisbane North PHN, the median length of stay prior to death in 2023/24 was 18.8 months. (55)

In Australia in 2021/22, 30.2 per cent of people were deemed to be palliative on admission (under conditions of the previous Aged Care Funding Instrument (ACFI)); 95.4 per cent of exits for people receiving palliative funding were due to death. (19)

In 2024, there were an estimated 185,000 Australians living in RACHs, with evidence suggesting that 92 per cent would benefit from palliative care. Despite this high level of need a study of those over 65 years in a RACH between 2012-2016 found just 3 per cent saw a palliative care physician. (53)

There is a persistent gap between palliative care need and service provision within RACHs. Barriers include limited awareness of palliative models and pathways among RACH staff, insufficient training in end-of-life care, and fragmented connections with primary care and specialist palliative outreach. (53) Addressing these gaps through staff education, earlier needs identification, and more consistent clinical involvement will be critical to improving resident and family outcomes as people approach end-of-life in RACHs. This is discussed further in section 4 of this Report.

2.3 Hospice Care

Hospices provide a more holistic model of care to enable individuals to die outside of hospital where they are unable to stay at home. Over recent decades there has been a shift away from the traditional hospice model of care towards a more medicalised acute hospital setting. However, community demand for hospice services is now increasing (particularly for adults in the region) and service providers noted significant demand for these services.

Within the North Brisbane and Moreton Bay region there is one dedicated children's hospice that serves all of Queensland, Hummingbird House, which is located on Brisbane's north side in Chermside. (57) Hummingbird House has a hospice capacity of 10 beds, but it is understood that current capacity is limited due to funding and workforce and only able to support five families within the hospice at any one time. There is a wider network of families supported by this service including through the provision of respite care. There is no adult hospice service in the North Brisbane and Moreton Bay region.

Service providers and peak bodies across the North Brisbane and Moreton Bay region identified a key gap in adult hospice services in the region and identified this as a key reason for the majority of palliative care consumers dying in a hospital setting across the North Brisbane and Moreton Bay region.

"I would love that palliative care was actually taken seriously. And we don't just rely on the small number of services we have. Let's start looking at a hospice kind of service [for adults], this would be a far more holistic model of care."-
Palliative Care Service Provider

2.4 Hospital Care

Hospital care remains a central component of palliative care delivery, particularly for older Australians with complex or advanced illness. Within Brisbane North PHN there are seven hospitals offering specialist palliative care services, with 42 dedicated in-patient beds across the adult public system. These services are provided across the following hospitals:

- Caboolture Private Hospital (noting they do not employ specialist palliative care nursing or allied health staff)
- The Wesley Hospital (Private)
- Caboolture Hospital
- Redcliffe Hospital
- Kilcoy Hospital
- The Prince Charles Hospital
- Royal Brisbane and Women's Hospital (consulting service with no inpatient beds).

Out of region locations servicing the region:

- Queensland Children's Hospital
- St Vincent's Private Hospital
- Mater Hospital, Brisbane

Palliative care-related hospital admissions in Brisbane North PHN are higher than both the Queensland PHNs and national averages across all age groups. In 2022–23, the rate of hospitalisation for palliative care was 43.7 per 10,000 population in Brisbane North PHN, compared with 39.8 for Queensland PHNs and 38.6 nationally.

Admission rates increase with age, with the highest rates observed in those aged 75 and over (359.9 per 10,000 compared with 315.1 for Queensland). Both cancer-related (19.8 compared with 17.4) and non-cancer palliative hospitalisations (23.9 compared with 22.4) are above the state average, reflecting the broad spectrum of palliative needs. (19)

These trends highlight that hospital care continues to serve as a critical access point for palliative support, particularly for older adults and those with complex care needs. The increasing rates of palliative care hospitalisation outline the need for proactive community-based support, earlier identification of palliative needs, and improved coordination between primary, residential, and specialist services to ensure timely, person-centred care and reduce potentially avoidable hospitalisations.

> *“The main reason people end up in hospital is because they can’t access/afford personal support care at home. Alternative sources of funding are almost impossible to find. This is probably the biggest challenge we face.”*- Palliative Care Service Provider

Hospitalisation rates are also influenced by socioeconomic status. Only areas with a higher socioeconomic status had lower palliative care hospitalisation rates than the national average in 2022/23. (19)

Palliative care related hospital admission rates remain high despite an acknowledged desire to die at home. Key reasons identified in consultation were:

- a lack of government funding to support nursing and personal care needs at home. Individuals often don’t have the financial support required to remain at home and the only viable alternative it to be admitted to hospital
- scope of practice can lead to problems with many personal care workers, disability support workers and enrolled nurses unable to administer breakthrough medications in the home to alleviate pain (noting this can sometimes be limited by how this medication is required to be administered). This means that individuals can be experiencing such significant pain that the only option is to attend hospital to receive the medication they need
- some individuals require complex care due to comorbidities, disability requirements, or distress and where these become too difficult to manage at home there may be a need for the person to be cared for in a hospital setting.

Further discussion on key barriers to accessing care are included in Parts 4 and 5 of this Report.

Consumers and service providers highlighted a need for comforting physical spaces within palliative wards that can accommodate both the individual and their family. Some providers offer large, comfortable rooms with outdoor areas, quiet places and additional carer rooms. This ensures space for visitors and large families and brings some dignity and comfort for the individual dying.

Any physical hospital space also needs to be designed to provide a culturally safe environment that supports a range of cultural backgrounds. It was noted that some hospitals within the region provide the supportive palliative environment well, and others could be improved.

A further gap highlighted by service providers was in facilitating the transition from paediatric care to adult services which can create added stress for the young person and their family as they navigate the system.

It is also noted that there are likely to be instances where people are dying in an acute medical hospital ward and not in a palliative care ward. Where this is the case, the consumer may not have access to palliative care services. There are current limitations in data regarding the prevalence of this across the region.

Key Finding 5: The Brisbane North PHN region includes three specialist palliative care services which provide home care, one children’s hospice, and seven public and private hospitals which provide adult specialist palliative care. These services are also supported by a wider service system including residential aged care homes, community pharmacies, general practices, additional hospitals and urgent care clinics.

Key Finding 6: Service gaps reported in palliative and end-of-life care for the region include the lack of adult hospice services, transition from child and youth services and appropriate end-of-life spaces that accommodate different cultural and family needs.

Key Finding 7: While there is a strong consumer preference to receive palliative and end-of-life care at home, only a small number of people actually die at home, with the majority dying in a hospital setting. The North Brisbane and Moreton Bay region has higher hospital admission rates for palliative care than both the national and Queensland average.

Within the Brisbane North PHN boundary there is a higher rate of hospitalisation for palliative care (43.7 per 10,000) than both the Queensland (39.8 per 10,000) and national average (38.6 per 10,000) and is likely due to a lack of alternative services such as an adult hospice and a need for increased community-based supports which limit capacity and choice in home and community-based palliative care.

Part 3: Needs and circumstances of those requiring palliative care

This section describes the needs and preferences of health consumers requiring palliative and end-of-life care. This includes discussion on consideration of holistic needs including spiritual care and advanced care planning, as well as specific needs related to priority cohort groups.

3.1 Death and grief literacy

Culturally competent palliative and end-of-life care encompasses holistic approaches, trauma-informed practices where relevant, and attention to age, spiritual beliefs, and other individual characteristics. Strengthening workforce capability around death and dying conversations, cultural competence, improving service coordination, and reducing stigma and discrimination are essential to ensure care is respectful, appropriate, and responsive to the diverse needs of people with life-limiting illness. (58) (4).

In addition, service providers noted there is a need to build community capacity and engagement in relation to death and dying and to better promote consumer rights, choice and control for to end-of-life care and funerals/ celebrations of life. Service providers reported a lack of death literacy nationally which may lead to challenges in providing holistic care beyond just medical needs at end-of-life stages (including spiritual care, death planning, managing psychosocial needs, and addressing trauma). Some noted they are seeing social supports such as death cafes and community events with older people where Advance Health Directives, VAD and wills are discussed in the region, but it was also noted that there can be a reluctance for consumers to listen to this information until someone is at a palliative or end-of-life stage.

> *“We are starting to see some shifts in community discussions around death and dying, but we have a long way to go. There remains a lot of fear about dying.”*- Palliative Care Service Provider

The period following death can be tumultuous time for family and carers and palliative care must support families for a complete care experience. It is important to consider the emotional complexity of grief and bereavement whilst also noting the unique logistical and administrative burdens.

There is limited access to support and counselling for family and carers as they experience grief and bereavement following a persons' death. Vulnerable individuals are also at risk of developing complex grief or prolonged grief disorder, in particular those from a low socioeconomic background. One service provider noted that children 12 years and above are often well supported through programs such as Camp Quality, but there are not the same supports for children and families under 12 years.

In recognition of this gap, it is noted that Metro North Health have recently established a grief and bereavement service across the region.

> *“Bereavement follow up needs to be flexible because families grieve in different ways. It doesn’t follow a timeline.”*- Palliative Care Service Provider

Service providers across the region noted that improving conversations around grief and bereavement at a community level is expected to help normalise the grief process as a shared and normal experience that requires social support.

3.2 Cultural and/or spiritual needs

Palliative care must be equitable, accessible, and culturally safe for all Queenslanders, delivered when and where it is needed. (4) Evidence and policy guidelines emphasise that culturally and spiritually responsive care improves patient and family outcomes, particularly for priority populations such as Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds, LGBTIQA+ communities, and people with disability. (14)

Historically, spiritual care used to be heavily integrated into the palliative care model however this changed following the subspecialisation of palliative care, which led to a focus on a more medical approach aimed at addressing physical pain. Spiritual care is currently often left to the discretion of service providers to implement this within the medical approach to end-of-life care- and has often been provided within a religious context.

Compassionate Communities (105)

Compassionate Communities is a public health movement and approach, based on work by Professor Allan Kellehear, which seeks to reclaim the community's role in supporting people with serious illness, ageing, dying and grief. Compassionate Communities encourage the strengthening of place-based naturally occurring networks of service providers, family members and carers and those who are at palliative and end-of-life stages to promote emotional, social and spiritual well-being as well as physical health. Its key aim is to improve the experience of death and end-of-life care.

The core principles behind Compassionate Communities include:

- There should be a shared responsibility across the community and should not be the sole responsibility of health practitioners;
- There is a need to develop the community's death literacy and grief literacy including through education, conversations and practical skills;
- There should be mobilisation of naturally occurring networks of support working alongside formal health and palliative services; and
- Examples may vary greatly and should be dependant on place-based characteristics.

The Commonwealth Department of Health, Disability and Ageing commissioned a report on the effectiveness of Compassionate Communities across Australia, which found that while there are examples of success, there can be challenges in the sustainability of these models due to funding.

In the Australian context, spirituality is the way that humans express meaning and purpose, and is about human connection to the significant or sacred. Importantly, it is distinct from religion, although it may include links to religion for many people. It is seen as a key aspect of providing holistic care alongside physical, psychological and social needs. (59)

It is noted that there can be misconceptions from the community in relation to the current provision of spiritual care by community organisations. For example Karuna, who are one of the key providers of community based palliative care in the North Brisbane and Moreton Bay region, are a Tibetan Buddhist based organisation, however they support the spiritual needs of every individual, and are not limited to a specific religious context.

Further barriers to appropriate spiritual and cultural care include a lack of cultural understanding and competence among healthcare providers, which can limit engagement, trust, and access for diverse populations. Addressing this requires integration of guidelines and pathways that support care tailored to cultural and spiritual needs, professional development for healthcare staff, and ensuring compassionate, person-centred care. (58)

More recently, service providers and stakeholders have reported a shift in consumer expectations regarding access to spiritual care. It was seen as being applicable to every individual, no matter their background. Support may also include addressing fears and concerns in relation to death to make the end-of-life experience more peaceful.

> *"We need to make sure that every patient has access to appropriate psychosocial and spiritual care. It has to be done together or it is only half a service."*- Palliative Care Service Provider

This balance between medical, cultural and spiritual needs extends to the post-death period. There is a need for increased acknowledgement of grief and bereavement and memory making and how this can be best facilitated during the end-of-life phase of care. Different cultures have unique preferences for how death is experienced and these need to be better understood and prioritised.

3.3 Advance care planning

Advance care planning (ACP) enables individuals to make and communicate decisions about their future treatment, care, and acceptable outcomes. It ensures that preferences are documented, respected, and integrated into care delivery, supporting person-centred decision-making at the end-of-life. (4)

In Queensland, types of documents which fall within advance care planning include Advance Health Directives, Enduring Power of Attorney and Statement of Choices. Acute Resuscitation Plans are sometimes included in ACP, but are not traditional ACP documents. (60)

Despite its importance, ACP is not yet offered as a standard part of routine healthcare. Palliative

Care Australia in a 2025 study, found that only one in three Australians have taken steps to plan for future health care. Of those, just 12 per cent completed ACP with a health professional, highlighting a reluctance to discuss end-of-life issues in clinical settings. Further, only one in five stored their ACP with a doctor, meaning preferences may not be available when decisions are needed most. (61)

Access to 21,020 Advance Care Planning documents has been made available to clinicians (including the Queensland Ambulance Service) for residents of Brisbane North PHN region via the ACP Tracker on The Viewer /Health Provider Portal. (62) This represents 11.9 per cent of all records lodged statewide. In the Brisbane North PHN region, 72 per cent of ACP documents stored on the ACP tracker originated from hospitals, the most common being an enduring power of attorney document representing 49 per cent of documents in 2024/25. (62)

From August 2024 to July 2025, the Statewide Office of Advance Care Planning recorded 1,399 new ACP documents were completed, 2,197 were reviewed and 5,657 ACP discussions were documented. The majority of ACP activity can be attributed to nurses and midwives (56 per cent), medical practitioners (41 per cent) and pharmacists (3 per cent). (62)

The ACP tracker in 2024/25 recorded 125 instances of ACP being declined. The factors identified with reduced uptake include death literacy and perceived cost.

Community awareness and education about ACP is critical to increased adoption. The Statewide Office of Advance Care Planning plays an important role in embedding ACP through education, advocacy, and awareness campaigns. (58) Tailored, culturally appropriate engagement is also needed, as culturally and linguistically diverse communities often have lower awareness and, in some cases, cultural or religious reservations about ACP. However, when introduced appropriately, uptake may be increased. Building ACP knowledge and normalising its role across all communities is essential to safeguard individual preferences and avoid care that is inconsistent with patients' values. (4) ACP also reduces the perceived burden on partners and supports inclusive, person-centred care. (63)

Stakeholders felt the conversation around ACP needs to start as early as possible, noting there can be a reluctance to initiate the process amongst healthcare providers. Commonly, individuals with dependents are often hesitant to commence ACP as they view it as a sense of failure or giving up. Instead, ACP should be perceived to be about living well and dying well.

"It is all about having the conversation, who it is you trust and identifying those who have nobody."- Palliative Care Service Provider

"Palliative care education and ACP education needs to start a lot earlier."- Palliative Care Service Provider

Where an ACP document is not in place and the individual no longer has capacity, a Statement of Choices can be created which is an initiative of the Statewide Office of ACP within the Queensland Government. A Statement of Choices is not legally binding in the same way as an Advance Health Directive but is a values-based document that can be completed by the individual (Form A) or on behalf of the individual outlining what their wishes and preferences might have been which can help to guide treatment (Form B). (64) This can help service providers ensure they support an individual's preference in end-of-life care.

3.4 Voluntary Assisted Dying

Voluntary Assisted Dying (VAD) provides a legal option for eligible individuals to end their life in a controlled, supported, and lawful manner when experiencing intolerable suffering from a terminal illness. (58) In Queensland, VAD legislation permits access under strict eligibility criteria, including a confirmed diagnosis of a life-limiting condition, decision-making capacity, and informed consent. (65)

A common misconception is that palliative care is only for people who are imminently dying and that it is synonymous with VAD. (58) However, palliative care focuses on improving quality of life and alleviating suffering at any stage of a life-limiting illness, whereas VAD is a specific legal option for end-of-life choice. Clarifying this distinction is important for patients, families, and healthcare providers to support informed decision-making. (58)

Access to both high-quality palliative care and the option of VAD allows individuals to exercise autonomy while ensuring comfort and dignity. Despite, initial reluctance and fear surrounding VAD, over time the perception has slowly shifted and the focus is now on the choice that it provides. In keeping with the data from the VAD team, service providers noted that many exercise an interest and plan for VAD, but don't end up implementing this at their end-of-life because they feel supported in their end-of-life journey. One service provider also noted that for certain conditions such as motor neuron disease, the option of VAD has reduced suffering for many.

"This is an end-of-life option that can give you choice."- Palliative Care Service Provider

Support workers and nurses are limited in the information they can provide to patients regarding VAD by law with only medical practitioners and nurse practitioners allowed to initiate a VAD conversation legally. In practice this means that many health professionals provide information in relation to VAD services if they are asked, as required by law, but they cannot volunteer this information. It is noted that there are obligations under Queensland legislation to not impede access to VAD information and services for those seeking information. Some service providers did raise concerns about consumer knowledge that the VAD service is available to them, and one service provider noted a need for specific education and training of the GP workforce to help consumer awareness of VAD in Queensland.

In 2024/25, 1,072 people in Queensland died by VAD administration, contributing to three per cent of total deaths in Queensland. 72.7 per cent were via practitioner administration rather than self-administration. (65) In 2024/25, there were 226 authorised medical practitioners, 26 authorised nurse practitioners, and 218 authorised registered nurses in Queensland that were able to administer VAD. (65) In Queensland, 66.9 per cent of people who requested VAD in 2024/25 were 70 years old or more with a median age of 75 years. (65) Of these, the primary diagnosis of people assessed as eligible for VAD was cancer (76.7 per cent), respiratory diseases (9.4 per cent), neurological disorders (6 per cent) (which was also the experience in the Metro North VAD service). (65) In Queensland 75.8 per cent of people requesting VAD in 2024/25 had engagement currently or previously with specialist palliative care services, compared with 98 per cent in the Metro North region. (65)

In 2023, Metro North VAD support service received 284 referrals, and this grew to 381 in 2024. (66) In the first nine months of 2025, 253 referrals were received. (66) Majority of VAD referrals come from Metro North staff (50 per cent), the Queensland VAD support and pharmacy service (32 per cent) and self-referral (12 per cent). (66) There is a requirement for three assessments to be eligible for VAD, and there is a minimum period of 9 days to complete this process (noting in some appropriate cases this can be expedited). Of those initially seeking information about VAD, about one third are estimated to utilise voluntary assisted dying to end their life. The Metro North VAD team reported workforce and funding shortages which are leading to some delays in the VAD approval process - which usually takes around 15-20 days.

"Access to the VAD service needs to be timely, and access takes longer on the north side of Brisbane than the south-side."- Palliative Care Service Provider

3.5 Clinical Complexity

People with palliative care needs often experience additional health and support requirements that contribute to clinical complexity. This complexity is heightened for individuals who have co-existing disabilities or chronic conditions that require ongoing management alongside palliative care. Feedback from disability consultations highlights that these individuals may have distinct care needs - such as specialised equipment, communication supports, or assistance with daily living - that are not always recognised within traditional palliative models.

From a health system perspective, greater attention is needed to ensure that these overlapping needs are understood and integrated into care planning. Coordination between disability, primary, and palliative care services is essential to provide holistic, person-centred support that acknowledges both health and functional needs throughout the end-of-life journey.

"Many think it [end-of-life care] is only for cancer but what about COPD, heart failure, end stage kidney disease."- Palliative Care Service Provider

Additionally, community service providers have observed an increased in referrals due to chronic disease rather than the typical malignant presentations. This brings a whole new element of clinical complexity and care needs with it.

3.6 Trauma

While the experience and processing of trauma may disproportionately affect some priority cohort groups than others (as discussed under section 3.9) an understanding of this more holistically in end-of-life care is important.

Research suggests that palliative care can act as a powerful trigger in resurfacing trauma, as often people in their last stages of life go through a psychological process of life review. This can lead to heightened intrusive recollections of traumatic events, intense feelings which may include distress, and may result in the individual seeking closure, making amends or establishing a legacy in some way. (67) (68)

"The processing of trauma needs to be better included and recognised in end-of-life care. It is not the same as mental health support."- Peak body stakeholder

3.7 Family and carer needs

Family members and informal carers play a central role in supporting people with life-limiting illnesses, with needs spanning both the whole palliative care period including end-of-life and bereavement. Many carers report feeling unprepared for the practical, emotional, and clinical responsibilities involved, often stating they "don't know where to start" when coordinating care, managing symptoms, or navigating services. (4) In discussion with carers and family who have supported people with palliative and end-of-life care there was confusion, and a lack of GP and primary care support in awareness of and linking to available services.

"There is no structured and consistent palliative care process which can be confronting. It also leads to inconsistency in the experience with some I have helped having a good experience and others a really traumatic one."- Palliative Carer within the region

In 2022, 11.6 per cent of persons under 65 years old in Queensland were in a carer role: 7.2 per cent as non-primary carer, and 4.4 per cent in a primary carer role. (69) On average, carers were aged 50 years in Australia, and 38.6 per cent of carers in Australia actually had a disability themselves:

- 59.6 per cent of carers over 65 years old had a disability
- 43.8 per cent of primary carers had a disability. (69)

The primary carer was most likely to be a spouse (37.4 per cent), a child (29.1 per cent) or parent (24.7 per cent) and: (69)

- of those with spousal relationships, 59.5 per cent were aged over 65 years old
- 59.2 per cent of those providing care to a parent were aged 45-64 years old
- 82.7 per cent of primary carers in Australia resided in the same household as their person.

The 2022 analysis indicated that only 31.8 per cent of primary carers in Australia reported satisfaction with the range of services available to assist with the caring role. (69) Many carers are unaware of the alternative services and support available to them, with 12.4 per cent of Australian primary carers reporting the main reason for not using respite is that they are unaware of entitlement or services. (69)

Carer duties can lead to social isolation and mental health issues for many. For example, in 2022, 7 per cent of male primary carers in Australia reported not seeing friends or family outside of their household in the last 3 months; compared with 2.9 per cent of female primary carers. (69) 47.8 per cent of primary carers in Australia in 2022 reported they would like more contact with friends and family outside their household. (69) Carers may also be unable to leave the house for important life events and social engagement on some occasions due to the inability to source alternative care arrangements. It is noted that respite services are available across the North Brisbane and Moreton Bay region and that support may need to be provided in accessing these services to prevent carer fatigue and burnout, but accessing this can require significant care coordination.

"Often two or three parties are involved in lining up just one day of respite support." – Service provider

In engagement with carers and families across the region, there was recognition of the role that was required of them in health advocacy and care coordination for their loved one.

Families and carers also require support as they navigate the process of death and dying. Funeral arrangements and the immediate next steps following death are often unknown or unclear and this can exacerbate stress and grief. Whilst one cannot truly prepare for the loss of a loved one, having a roadmap in place and some direction can support families and allow them to focus on what is truly important. Families reported they are left to navigate their grief and service provision at this complex time on their own.

“Families are asking questions, but they don’t get the answers because everyone is afraid.”- Palliative Care Service Provider

Based on the above, carers and families within the region reported a need for a centralised, single source of information to guide individuals, carers and families through the palliative care, end-of-life and funeral/ celebration of life process.

Key Finding 9: Contemporary and consumer-centred approaches to end-of-life and death care could be improved across the region.

Specific examples linked to the feedback from stakeholders across the region include:

- shifts in language from pastoral care to spiritual care to be more inclusive
- ensuring timely support where voluntary assisted dying is requested and improving information access
- strengthening end-of-life and death-based services which accommodate non-traditional approaches and beliefs
- improving the understanding of consumer and family’s rights and choices around end-of-life and death and funeral arrangements
- supporting trauma processing and life review at end-of-life stages.

3.8 Social isolation

Many palliative patients experience social isolation, which can compound the challenges of managing a life-limiting illness. (70) People living alone without a caregiver often face greater emotional distress, limited access to support, and difficulties navigating home-based care. (70) They are also less likely to die in their preferred place, highlighting the impact of isolation on both quality of life and end-of-life outcomes.

Priority cohorts, including older people, those with disability, culturally and linguistically diverse backgrounds, and people experiencing homelessness, face worsened outcomes due to fewer informal supports and structural barriers such as travel, mobility, and stigma. People with dementia have higher risk factors for social isolation as the disease progresses.. (71)

There were consistent concerns from both service providers and consumers about the vulnerability of people who are socially isolated. Carers and family members often take on a crucial advocacy role, navigating complex health systems, communicating with multiple providers, and ensuring that the person’s wishes are understood and respected. This raises the question of who is providing this advocacy and direction to those who have nobody and may be socially isolated.

For those without such informal supports, this advocacy gap can lead to fragmented care, unmet needs, and limited access to services. Social isolation may result in individuals missing out on timely referrals, advance care planning, or comfort measures, as there is no one to coordinate or speak on their behalf to ensure their wishes are met.

“If you live alone, and you have no family, you can’t die at home so who’s responsibility is that? I just don’t know.”- Palliative Care Service Provider

Often, for these socially isolated individuals, dying at home is simply not a viable option due to the lack of supports available to them. This highlights a critical need for systems-level solutions - such as dedicated care coordinators or community advocates - to ensure equitable access to palliative and end-of-life care for those without personal support networks.

Carers also experience significant social isolation. The first results from the 2024 National Carer Survey indicated that around 60 per cent of respondents felt socially isolated, with about half experiencing high or very high levels of psychological distress. (72) Supporting a loved one at the end-of-life often involves a tension between maintaining independence and seeking connection and support. For many older carers, independence- through managing household tasks or self-care- can come at the expense of social connection, leaving them more vulnerable to stress and burnout. (72)

“If the person doesn’t have somebody then the process is almost always a bad one. You need somebody to advocate for you at end-of-life to ensure your needs are met.”- Palliative Carer within the North Brisbane and Moreton Bay region

Key Finding 10: Carers and families report needing to provide health advocacy and act as the point of contact and communication for people at end-of-life stage.

Consultation with carers across the region identified that they played a critical advocacy role at end-of-life stages. This needs to be acknowledged by health professionals and the care workforce in service delivery.

Key Finding 11: Those who are socially isolated and who do not have family and carer supports are a specific priority cohort who may face challenges in accessing effective palliative and end-of-life care, exercising choice and control, and support in death planning. Models of care that provide strengthened care coordination, health advocacy and death planning need to be considered for this group.

Families and primary carers within the region emphasised the importance of the advocacy and coordination role they played at end-of-life stages and specifically identified those who are socially isolated as a key cohort group that need to be thought of in models of care to ensure they are supported in this important phase.

3.9 Priority cohort specific needs

3.9.1 Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander peoples face significantly poorer health outcomes than the general population, with earlier onset of ageing (50+ is by government standards considered aged) and higher prevalence of chronic disease.(73) In general, Aboriginal and Torres Strait Islander peoples presenting to community based palliative care are significantly younger than the mainstream population with a large proportion under 50 years, and, as a consequence, are unable to receive the funding for the care they require.

Cultural values and traditions strongly shape end-of-life care, including preferences to die on country, kinship rules, mourning rituals, and the viewing of death as part of a natural cycle. (73)

However, barriers persist - including limited awareness of palliative services, mistrust of Western medicine, taboo around discussing death, language and communication challenges, low cultural competence among providers, and under-representation of Aboriginal and Torres Strait Islander peoples within the workforce. (73)

In consultations, an ACCHO service provider reported that the priorities in providing palliative care for the First Nations population were:

- encouraging palliative care access in the first place
- reducing the number of Aboriginal and Torres Strait Islander people in hospital
- increasing the number of referrals from other community based palliative care providers to the ACCHO to ensure culturally appropriate care was supported.

> *"Our biggest concern is our Indigenous population, that they don't get a fair go. They need to be cared for in a different way to what people think they should be."-*
> Palliative Care Service Provider

An additional consideration is ensuring a culturally safe workforce. Non-First nations health workers report feeling prepared to provide palliative care but are often not confident in providing culturally safe care. Conversely, First Nations health workers can confidently provide cultural safety but may not be confident in delivering palliative care. Yarning circles have been implemented across some areas of the region for both groups of health workers to help develop the skills they may feel they are missing. Aboriginal and Torres Strait Islanders require a strength-based approach to care rather a deficit-based approach and this is improving due to changing models of care and education such as First Nations Palliative Care project discussed above.

Culturally safe palliative and end-of-life care is strengthened by a First Nations workforce who can offer trust and connection to patients and culture. First Nations people may prioritise specific cultural traditions such as soil being used to symbolise a returning to country and specific rituals such as a smoking ceremony. First Nations providers are better positioned to facilitate a person's cultural needs and ensure culturally safe care.

A significant proportion of this caring workforce is also female, and this can lead to difficulties in treating males and adhering to men's business.

Health workers have to balance providing the best clinical care with culturally safe care and this can lead to fear of doing the wrong thing in many cases.

First Nations Palliative Care Project (Queensland Health) (104)

Over the last 12 months, Queensland Health have established a state-wide First Nations Palliative Care project to improve capacity and capability across the public health system (including in ACCHOs and primary care settings) to meet the palliative and end-of-life needs of First Nations Queenslanders. It has been established based on an identified need to develop an evidence based, culturally safe and culturally responsive palliative and end-of-life care model, and has been informed from a robust consultation process with Elders and First Nations communities across Queensland.

The project has included the development of culturally appropriate resources and tools and has included advanced care yarning circles, yarning about morphine (including a brochure to help guide discussion with First Nations people and their families), videos that helps to support choice, storytelling and forms that support people in palliative and end-of-life care stages. It also supports Aboriginal and Torres Strait Islander health professionals to feel more comfortable in relation to palliative care discussion through the Statewide Clinical Yarning Circle, with topics hosted by clinical specialists. A clinical yarning circle is also available to non-Indigenous health professionals to ensure they are more comfortable in having palliative care conversations with First Nations Queenslanders that are culturally appropriate. Part of this work has also considered providing safe spaces towards the end-of-life and in death that support culturally appropriate ceremonies, pictures, connection to land and places large enough to accommodate First Nations families.

Continuity of care and developing trust is crucial amongst this cohort. The existing fragmentation of palliative care can exacerbate mistrust and avoidance of mainstream services as there is no connection developed between the patient and provider.

"We have a huge issue with ACP. We just cannot get people to do it. We really struggle to get those forms completed. It is such a taboo subject within this culture."- Palliative Care Service Provider to First Nations peoples

Another challenge is the reluctance to discuss death as it is considered taboo within Aboriginal and Torres Strait Islander culture. This creates problems in preparing ACP and ensuring their wishes and cultural needs are met as they approach end-of-life. The Institute for Urban Indigenous Health (IUHI) have implemented alternative settings such as 'Arts and Yarns' workshops where ACP conversations can occur to create a safe and comfortable environment. Service providers across multiple settings highlighted the importance of providing tailored resources and approaches to the First Nations population regarding ACP, grief and bereavement and after death care to ensure these resources are accepted and culturally safe.

There can also be stigma surrounding the use of pain medication such a morphine. Within this culture, natural death is considered important and thus there may be a preference to avoid the use of medication. Additionally, medication access may be restricted to prevent misuse and ensure appropriate storage with individuals reporting to a clinic to access their medication. This can lead to shame due to the taboo nature of medication within this culture. There has been some change in this conversation with the introduction of 'morphine yarning' to help shift the perception of the symptom burden.

Grief and bereavement are also experienced differently in this population. Individuals may come from low socioeconomic background, have a history of trauma, and/ or have had to deal with higher rates of death, and thus complex grief is more common.

Several initiatives are in place to support First Nations people through death, and grief. The Indigenous Program of Excellence in the Palliative Approach (IPEPA) have introduced a biography service for First Nations people to maintain legacy whilst Aboriginal Community Controlled Health Organisations (ACCHOs) within the region support First Nations palliative care and counselling. Many also often wish to seek or speak to local Elders during this time for connection and bereavement support. (74)

"First Nations people are quite fluid, it is all about connection and connectedness, both physical and social, emotional, cultural and spiritual."- Palliative Care Service Provider to First Nations peoples

"First Nations Australians support each other in the death process beautifully- they just don't talk about it."- Palliative Care Service Provider

3.9.2 People from culturally and linguistically diverse backgrounds

People from culturally and linguistically diverse backgrounds experience a range of barriers to palliative care shaped by language, health literacy, cultural and religious beliefs, family-based decision-making, fear or distrust of government, and limited culturally and linguistically diverse-specific resources, as well as difficulties accommodating cultural practices. (75) Prior migration experiences may also contribute to trauma, while communication challenges, discrimination, and limited understanding of funding options further impede access. (75) Time pressures in primary care add another layer of complexity, making it difficult to deliver culturally responsive care. (28)

Culture critically shapes perceptions of end-of-life needs, influencing beliefs about health, illness, and dying, as well as health-seeking behaviours and emotional responses to life-limiting illness. (75) Enablers include health workforce navigators, culturally competent practice, and targeted education and resources, which can support communication, improve access, and ensure care is culturally safe, responsive, and aligned with community needs. It was also noted that the culture and conversations in relation to dying and death differ greatly, with this being taboo in some cultures and in others this is discussed openly and well supported by local community.

Some settings are noted to be particularly difficult to navigate for people from culturally and linguistically diverse backgrounds. Emergency Departments can be quite overwhelming for non-English speakers in particular; however this may be the only place they are aware of to seek care. Additionally, it was reported that many health care professionals are not utilising interpreters as they should and instead communicating via family members which places the patient in a more vulnerable position where they are unable to directly communicate their wishes and ask questions. The funeral industry and post death journey can also be particularly difficult to navigate with limited interpreter support and cultural capability.

> *“Racism needs to be addressed within the hospital in order to provide safe care for all.” -* Family of palliative care consumer

3.9.3 Refugees

Many refugees experience complex health and social needs arising from disrupted lives, language barriers, loss of identity, and exposure to adverse and traumatic events. These experiences of trauma- often involving violence, persecution, displacement, and loss of family- can have lasting psychological and physical effects that shape how individuals perceive illness, death, and the health system. (76) Trauma can manifest as fear, mistrust, or avoidance of institutions, particularly when care environments or interactions unintentionally mirror past experiences of control or harm. It can also complicate communication, decision-making, and the establishment of trust with healthcare providers, making culturally safe, trauma-informed care essential. (76)

Refugees may additionally face barriers to accessing publicly funded healthcare, including Medicare eligibility issues, which can result in limited or delayed access to appropriate palliative and end-of-life services. (76) Addressing these barriers requires an understanding of the enduring impact of trauma and a commitment to delivering compassionate, flexible, and culturally responsive care.

3.9.4 People who identify as LGBTIQA+

People who identify as LGBTIQA+ can face unique barriers to accessing palliative care. These include collective trauma and grief, fear of discrimination or stigma including from religious institutions and health professionals, concerns about disclosing sexual or gender identity, legal issues, and mistrust of institutional care. (63) Social isolation may further limit family or community support, while non-disclosure of sexual orientation can lead to assumptions of heterosexuality or misidentification of gender, impacting care decisions. (63)

Service-level challenges include unsafe or non-inclusive environments, lack of staff awareness and training, systemic bias, and discrimination faced by the chosen carer. This can result in inappropriate healthcare decisions and increased burden on carers. LGBTIQA+ individuals often present with more advanced diseases and higher mental health needs, partly due to risk behaviours linked to experiences of discrimination. (63) As many community care organisations in the region are faith based, people who identify as LGBTIQA+ may find it difficult to find culturally appropriate care at home.

A key concern raised by peak bodies is the honouring of the chosen family by people who identify as LGBTIQA+, with extensive examples of how this has not been supported by health professionals in end-of-life care. In addition, it was noted that particularly for those who identify as transgender, the honouring of someone's chosen name is important even as they are dying, and that this also needs to be respected in the death process- including funerals and tombstones.

For older persons who identify as LGBTIQA+, particularly those with HIV, it was noted that there can be a significant distrust of religious organisations and hospitals and health professionals due to historical discrimination which can create significant barriers to access to community, hospital and residential aged care palliative and end-of-life care. It was noted that those who are HIV positive may have also lived through a traumatic period of almost dying, and who may have also witnessed a number of friends who died from AIDS- this trauma can also be a significant additional burden that needs to be well understood when supporting palliative and end-of-life care.

Advance care planning is particularly important for LGBTIQA+ people to safeguard their wishes legally and protect partners from disenfranchisement. Evidence shows that while more than half of Australian LGBTIQA+ participants had communicated their end-of-life preferences to their partner, only 29 per cent had an enduring power of attorney, 18 per cent an enduring guardian, and 12 per cent an advance care directive. (63)

3.9.5 People with disability

People with disability experience higher rates of comorbidities compared to the general population and are admitted to Emergency Departments and hospital at double the rate. (14) Specifically, barriers to palliative care include limited accessibility, communication challenges, poor health literacy, cognitive impairments, fragmented services, and lack of tailored care. (77)

A key barrier is "overshadowing," where health professionals attribute symptoms or presentations to the underlying disability rather than recognising end-of-life needs, delaying palliative care. (77) This phenomenon contributes to premature mortality and high rates of avoidable death, particularly among people with intellectual disabilities.

People with disability require individualised care planning, interdisciplinary care coordination, accessible information, and staff trained in disability-informed approaches. Ensuring equitable, person-centred palliative care can improve symptom management, quality of life, and dignity for people with disability.

Those with an intellectual disability can be particularly vulnerable due to impaired cognition and difficulty understanding. This can create challenges around informed consent and guardianship, potentially leaving these individuals vulnerable to the beliefs of another person that may not align with their own. ACP can also be a challenge due to cognitive capacity and health literacy limitations. (77)

Family members acting as surrogate decision-makers may also be reluctant or uncertain in making end-of-life decisions. Service providers reported that disability support workers are often willing to support the ACP process alongside the patient however there is a need for increased education on this legal process to protect the most vulnerable.

"Care for people who 'don't understand' and require more time and care in explaining what is happening is challenging, and not well met by service providers who have limited time."- Carer for palliative care consumer

Additionally, the NDIS packages often do not provide enough funding to support both the disability and palliative care needs of people with disability. Once their funding cap is reached, often the only option that remains is to go to hospital for care. If a NDIS participant wishes to upgrade their existing plan to account for their palliative needs, this can often take up to 6 months for approval, and many service providers reported the consumer died within this period.

"As soon as you say terminal illness the NDIS are not interested."- Palliative care service provider

It is noted that the NDIS (Supports for Participants) Rules make clear that the NDIS funds are to support needs directly related to the participant's disability and not to support services available through Australia's health system (such as palliative care). However, it is noted that in practice, people living with a disability may be able to access some additional support as they are approaching their end-of-life subject to meeting the NDIS reasonable and necessary criteria. In addition, there are also some life limiting degenerative diagnoses which may enable some people to access the NDIS (such as Motor Neuron Disease or Huntington's Disease) which cause decline in physical and cognitive function. This complexity in eligibility has been raised in the palliative care sector over the last few years but was not a key focus in the feedback provided by service providers and carers within the region for this Report. (78)

3.9.6 Socio-disadvantaged population (including those who experience homelessness)

Individuals experiencing homelessness or housing insecurity often require earlier access to palliative care due to shorter life expectancies and higher rates of comorbidities. (79) They face multiple barriers to care, including financial constraints, limited transportation, lack of access to technology, fragmented services, complex referral pathways, and stigma or discrimination, which can discourage engagement and delay treatment. Additionally, rising emergency department presentations and hospitalisations for homeless people over the past five years indicate increasing demand and strain on existing health services. (79)

Challenges in delivering care are due to the limited availability of specialist palliative service and workforce shortages, and poor integration across hospitals, emergency departments, primary care, and community services, which can create fragmented care experiences. This can add further barriers for people experiencing socioeconomic disadvantage. Strategies to improve access include coordinated care pathways, flexible service delivery models, targeted outreach, and support from health workforce navigators, which help individuals navigate health and social services.

The financial requirements of palliative care can also often lead individuals including carers towards homelessness as they may be making decisions between affording necessary care or paying rent. Within the Brisbane North PHN, there is also a distinct lack of hospice care available to adults meaning that there really is no place for them to go other than hospital.

“There is a big homeless population, particularly in Redcliffe. Their health needs are not met very well generally, but this is especially true in relation to their end-of-life needs.” - Palliative care service provider

3.9.7 Younger person with palliative needs

Paediatric palliative care focuses on the unique developmental, emotional, and educational needs of children and adolescents with life-limiting conditions. (1) Care is delivered through a consultative model, with the primary treating team supported by palliative specialists. Within the North Brisbane and Moreton Bay region, Children’s Health Queensland support all paediatric palliative patients, which reduces the need for most palliative care services.

Age-appropriate communication, education, and play are essential, and families should be actively involved in decision-making. Siblings and grandparents may also require support to manage the emotional, financial, and practical impacts of the child’s illness which is generally well integrated into the paediatric care model. (1) The Brisbane North PHN region is well positioned to provide this specialised care to children through the Hummingbird House hospice model. However, limited capacity and funding remain a problem in meeting service delivery needs.

Many paediatric cases involve rare or uncertain diagnoses, making advance care planning challenging. Additionally, paediatric palliative care is often provided over an extended timeframe, highlighting the importance of clear transition pathways from paediatric to adult services to maintain continuity of care. (1)

“Communication in transition of care is poor. There are lots of breakdowns. Multiple teams, it’s big and it’s complex. There is not one centralised port of call for these poor families.”- Paediatric palliative care service provider

There are additional complexities associated with paediatric palliative care as the child becomes older surrounding making medical decisions and guardianship. Adolescents may not be allowed to make their own medical decisions surrounding their care and this can lead to significant turmoil for the child and their family.

3.9.8 Those with neurodegenerative conditions including people with dementia

The disease trajectory of dementia and other neurodegenerative diseases is often unpredictable, complicating prognostication, decision-making, and advance care planning. ACP can be hindered by health provider, consumer, and carer and family’s lack of knowledge or comfort/confidence talking about capacity loss and end-of-life. In primary care ACP is further limited by time constraints, and in RACH can be constrained through care coordination challenges. (77) The conversations surrounding ACP for this cohort need to commence earlier prior to the onset of cognitive decline.

People with dementia and other neurodegenerative diseases frequently experience complex clinical needs, cognitive decline, and communication challenges, while families acting as substitute decision-makers may feel unprepared. Evidence suggests that greater carer knowledge increases the likelihood of choosing comfort-focused care, and patients emphasise being cared for "in place," staying at home as long as possible, and maintaining comfort at end-of-life. (77)

Despite the symptom burden of dementia being comparable to cancer, people with dementia often receive poorer quality end-of-life care. Improved navigation support, interdisciplinary collaboration, and service integration are crucial to provide timely, person-centred palliative care for this population. (77) (14) Some healthcare professionals may not recognise dementia as a terminal illness requiring palliative care. Translational interdisciplinary research is needed to translate evidence into practice and improve care delivery.

"It is different because of the cognitive shift that comes with dementia" – Dementia focused service provider

This population require advocacy due to their reduced cognitive capacity. Planning for end-of-life and death becomes more important due to the way in which an individual can rapidly decline. It is crucial to identify symptoms as early as possible and initiate conversations around ACP immediately whilst they have the capacity.

"Just to empower people with information [would be beneficial], so they are not flailing when decision making becomes critical" – Dementia focused service provider

Improvement in community care for dementia and other degenerative disease is essential to avoid unnecessary hospitalisation. There are complications in diagnosing dementia due to the nature of early dementia and waves of cognition changes. However, community care provides the opportunity to observe people at home and identify potential indicators and then facilitate their care journey from home. The hospital and emergency department can be an overwhelming and confusing places for those with dementia and thus developing alternative care pathways and referrals for these individuals would be beneficial.

3.9.9 Stolen Generation, Care Leavers and Forgotten Australians

Care Leavers present distinct and complex needs in palliative care arising from adverse life experiences, including family separation, abuse, and loss of identity. These experiences have fostered deep mistrust of institutions and heightened sensitivity to environments that resemble past care settings. Many have limited awareness of palliative care and associate it with traumatic experiences of death, leading to negative perceptions and reluctance to engage with services. (42)

"You have to unpack the pain story and look at it from a holistic lens" – Service provider

Fear of losing autonomy, difficulty communicating personal wishes due to learned silence, and the absence of family connections further complicate advance care planning. Identifying Care Leavers can also be challenging, as they are often hidden within the broader population.

Palliative care service providers discussed the importance of unpacking the pain story and truly understanding their journey and all the components. Once identified, it is essential that care approaches prioritise psychological safety, foster trust, and create space for individuals to express their identity and preferences with compassion and understanding.

3.9.10 People who are incarcerated

People who are incarcerated often have significant but under-recognised palliative care needs, largely overlooked due to their separation from the broader community. (48) High rates of comorbidities, substance dependence, and mental illness contribute to complex care requirements that are difficult to meet within correctional settings. Low health literacy coupled with the prevailing culture, marked by toughness and distrust of staff, can further discourage individuals from seeking care. (48)

The process of accessing palliative care is complicated within a prison setting due to rigid institutional processes, limited compassion and security concerns particularly in regard to transfers. Prison infirmaries are often chaotic and not conducive to the needs of a palliative care patient where a terminal cancer patient could be located next to a drug withdrawal patient. (48) Attitudes among prison staff, where security takes precedence over wellbeing, can also exacerbate these challenges.

Family engagement is often constrained by logistical barriers and strained relationships which can result in limited advocacy and support networks, while bereavement support is rarely available. These challenges are compounded by societal indifference, with public perception often limiting attention and resources for this vulnerable population. (48)

> *"To have specific palliative services coming in and supporting prisoners and offering them spiritual care. They deserve it just as much as anyone else if they are coming to the end-of-life. Their death is just as important as anyone else."* – Service provider

3.9.11 Veterans

Veterans often present with complex palliative care needs shaped by high rates of mental health conditions, including post-traumatic stress disorder (PTSD), depression, and substance misuse. These conditions can complicate symptom management and limit trust in health professionals, particularly where past experiences or unintentional triggers occur in care settings. Many veterans avoid disclosing their veteran status due to stigma or lack of a formal mental health diagnosis, which can hinder access to appropriate support. (80)

A strong culture of independence and resilience, often expressed as a "she'll be right" attitude, can deter help-seeking. Experiences of homelessness, family breakdown, and social isolation intensify vulnerability and limit access to consistent care. The transition from military to civilian life can be traumatic, with many feeling their lived experience is poorly understood or undervalued by health professionals. (80)

Administrative complexity within DVA benefit systems can further overwhelm individuals and delay access to palliative services. Of approximately 641,00 veterans in Australia in 2020, only 165,00 were registered as DVA clients (26 per cent). (80) Additionally, palliative care service providers can be reluctant to provide care to veterans due to limited funding and financial incentive for providers. For example, the DVA do not offer funding for afterhours visits meaning that primary care providers do not offer such a service.

Despite these barriers, veterans are often more open to ACP, shaped by their familiarity with death and direct communication style. Veterans express a preference to 'die with dignity' and it is crucial that palliative care is administered in a way that enables this. (80)

Key Finding 12: There are specific palliative care needs and challenges for some priority cohort groups, including but not limited to:

- **incorporating cultural and spiritual values and traditions**
- **language barriers to accessing care and utilising choice**
- **social isolation**
- **overshadowing**
- **non-inclusive environments**
- **supporting guardianship and decision-making**
- **late identification of palliative care needs**
- **a lack of trauma informed approaches**
- **addressing systemic bias and discrimination (including understanding how historical experiences of discrimination and bias might impact on individuals requiring care).**

The nuanced needs, trauma, stigma and discrimination that may exist for individuals who identify with one or more priority cohorts needs to be well understood by health professionals and the wider workforce that support palliative and end-of-life care. Increasing community capacity and engagement will also better support a positive experience for during end-of-life care.

4. Healthcare supply and provider barriers in the region

This section describes key barriers and enablers to palliative and end-of-life care from a service provider perspective from across the North Brisbane and Moreton Bay region. It is noted that the services provided across the region to consumers are discussed in section 2 and cover home based care, residential aged care, hospice care and hospital care settings.

4.1 Workforce

The Brisbane North PHN region has a number of palliative care services (as outlined in Part 2). Given this landscape, there is a need to ensure a sustainable workforce. The workforce is broadly grouped into two types – those who are trained and work in specialist palliative care, and those who provide generalist palliative care which include all other health, care and support workers.

4.1.1 Workforce shortages

The palliative care workforce is under significant strain. In 2023, of 6,742 medical practitioners in the Brisbane North PHN catchment, only 18 were registered as palliative medicine specialists, while 1,590 GPs in the region reported providing some palliative care. (81) The highest number of GPs within the SA3s are in Brisbane Inner, Brisbane North, Brisbane Inner- West, Chermside and The Hills District. Projections indicate the undersupply of palliative medicine specialists will increase from 23 per cent in 2021 to 32 per cent by 2027. (82)

Among 22,425 nurses, 50 worked in hospices, 1,507 in community health services, and 656 in general practice, with the remaining majority concentrated in hospitals. (81) Although workforce numbers have grown moderately across the state, there is a maldistribution which favours Southeast Queensland.

Shortages in the palliative care workforce are also reported across Australia, with research undertaken for Palliative Care Australia reporting that 69 per cent of specialty service providers reported difficulties in recruiting staff, and 48 per cent reported difficulties in retaining staff. This occurs in a context of rising demand due to a growing and ageing population, as well as reported growth due to the introduction of VAD. Workforce retention is reported as being difficult due to workload pressures in a constrained funding environment, ethical alignment on issues such as VAD with their employer, and psychosocial hazards including burnout due to the emotional hazards of providing palliative care. (83)

Workforce supply and attraction into palliative and end-of-life care is further constrained by limited formal palliative care education in medical and nursing schools, leaving many clinicians without an understanding of palliative and end-of-life care and not seeing this as an area of future focus or specialty. (7) Low numbers in the private system restrict capacity for home and community-based care. (82) Additionally, gaps in data on patients receiving such care can hinder effective workforce planning for the future. (84)

Service provides noted that the nursing component within community palliative care is shrinking with the ageing workforce. There are limited formal structures or processes in place to support pathways into palliative and end-of-life care and many reported learning about how to provide this care through on the job experience. Access to allied health professionals, particularly in the community context, is limited for palliative and end-of-life care.

> *“Workforce is the biggest issue – getting skilled people into our health service. In last five years, many senior positions have retired, and a lot of experience has been lost.”* – Service provider

> *“My biggest concern is who is going to look after these people in the future.”*– Service provider

4.1.2 Workforce capability in palliative and end-of-life care

A number of specialist services providers consulted within the North Brisbane and Moreton Bay region noted that they had acquired their knowledge about how to deliver holistic palliative and end-of-life care by being exposed to other palliative care professionals and dedicating more time, research and passion to this area.

This suggests that, at present, on the job learning and transfer of knowledge and capability from specialist practitioners and workforces is critical to supporting capability and capacity across the palliative and end-of-life care workforce. It also suggests that more formalised training can be developed to help improve confidence, competence and capacity in relation to palliative and end-of-life care. The research by Palliative Care Australia suggested that 85 per cent of survey respondents were interested in receiving further education and training, suggesting an appetite across the broader health and care workforce. (83)

> *“We need an education package for workers on death and dying and how to approach the subject.”* – Peak body representative

To address workforce shortages and knowledge and education around palliative care, some work is being progressed to directly target palliative care experience within the workforce through PEPA (Practical Experience in the Palliative Approach). This focuses on offering short 3–5-day placement experiences within specialist palliative services to help increase the capacity and capability of the palliative care workforce. Between January 2023 and October 2025, 17 workers in the Brisbane North PHN region, including Registered Nurses, General Practitioners and Aboriginal Health Providers, have undertaken PEPA placements, representing 8.1% of all PEPA Queensland placements. (85)

Brisbane North PHN have been working on building knowledge, skills and confidence of the workforce through several initiatives under the Greater Choice for At Home Palliative Care Measure. These include joint education events for prescribers and pharmacists, training for aged care staff in holding conversations about death and dying, and practice framework providers can use when supporting a person with disability through end-of-life.

4.1.3 Cultural capability

The palliative care workforce faces significant challenges in delivering culturally capable care. There is limited access to relevant cultural awareness and competency training, leaving staff ill-prepared to address the needs of underserved groups. (58) Misunderstandings and communication barriers between clinicians and patients, along with experiences of stigma, discrimination, and racism, further compromise care. (58)

Workforce approaches often treat culture as static, overlooking diversity within groups and individual patient needs, and limiting the adoption of trauma-informed care. These gaps hinder equitable access to palliative care and the ability of staff to provide care that is responsive, inclusive, and culturally safe. Many service providers reported a need to implement some kind of training or accreditation process for their staff to ensure culturally safe care.

It is noted that through programs discussed earlier in this report, such as the First Nations Palliative Care Project, work is being undertaken to strengthen culturally appropriate palliative care.

4.1.4 Recognising the wider end-of life workforce

Stakeholder engagement across the region identified the clear need for support in holistic end-of-life care that was not just limited to the medical model and physical needs. Death doulas, bereavement counsellors and other support roles within the wider workforce have the potential to play this role and ensure consumers, carers and families are supported with a positive experience at their end-of-life stage. It is also acknowledged that funeral workers (including funeral directors) also play an important role in supporting families in death planning, and there are an estimated 7,600 of these employed in Australia. (86)

4.1.4.1 Death Doulas

A death doula or end-of-life doula works with a palliative care consumer and those close to them to have their wishes and preferences supported at their end-of-life stage, including supporting their death and funeral arrangements. This role is not clinically focused but supports holistic needs including navigation and coordination of place-based services, advocacy and independent support, spiritual care, help in navigation of advance care planning, VAD, wills and guardianship (noting they are not lawyers). It also provides support in addressing fears around death and dying using trauma informed approaches (noting they are not psychologists). They work alongside health professionals, support workers and counsellors.

In Australia, their role is emerging, and regulation of this profession is developing with a national peak body that has been established- Holistic End-of-life and Deathcare Australia (HELD). There is an uneven distribution of the death doula workforce across the region, with an estimated 33 per cent of trained doulas based in South-East Queensland. (87) As of October 2025, 117 people had completed the 4 days intensive course to become an end-of-life doula in Queensland, with three people who had completed the Certificate IV (or skill set supervision equivalent). (87) It is noted the Certificate IV is a recently approved qualification for death doulas, and currently the only Registered Training Organisation where this course is available is in Newcastle, New South Wales.

The death doula workforce is increasing in demand, and is projected to grow by 10 per cent per year, and include a national workforce of approximately 170 by 2029. (87) Death doulas provide a unique relationship with those who are dying and the family as they are with them through the entire journey, specifically following death. This can create a sense of connection through continuity of care which is invaluable to ensure the individuals wishes are upheld and support the family as they navigate grief. They also play a key role in helping with wider needs of the person beyond medical care at their end-of-life which may include funeral planning and arrangements, addressing fears, care coordination and navigation and providing spiritual care. At present, death doulas are typically funded by the consumer and or their family, and this will mean that some priority cohorts, particularly those more likely to be of a lower socio-economic status may not be able to utilise this service due to cost.

"We provide that relationship with the consumer that the various palliative care channels don't. We have the time and are not bound to a schedule or shift time." – Death doula service provider

4.1.4.2 Grief and Bereavement Counsellors

There is growing recognition of the need for grief and bereavement counsellors in Australia, with data suggesting 1 in 10 persons impacted by the death of a loved one experience Prolonged Grief Disorder, which is a complex condition requiring intervention and support. While grief is recognised as a natural response to loss, Prolonged Grief Disorder refers to intense persistent grief that impact daily functioning beyond a period of 12 months. (88)

Grief Australia (formerly the Australian Centre for Grief and Bereavement) have introduced certifications to strengthen workforce capability in this area including the Certified Bereavement Practitioner Program and work is being progressed on National Standards to further professionalise this workforce. (89)

Key Finding 13: Ensuring a sustainable palliative care health workforce remains a key challenge and may worsen in light of growing service demand. Education and training of the workforce in culturally safe palliative and end-of-life care a remains a priority.

Key Finding 14: Palliative and end-of-life care models need to consider the emerging roles of death doulas and grief and bereavement counsellors in providing holistic and consumer centred care.

Developing a region-specific workforce strategy including all service providers may assist in implementing attraction, recruitment, retention and capability development strategies that support the small but specialist palliative care workforce, palliative care knowledge and understanding across the wider health and care workforce, and recognition of emerging roles including death doulas and grief and bereavement counsellors.

4.2 Scope of practice

A number of community-based service providers noted that there are scope of practice restrictions regarding the administration of medications, particularly in relation to breakthrough pain management and syringe drivers which may not be undertaken by personal care workers, disability support workers and enrolled nurses. In many cases it was reported that families and carers will not be aware of this and that there are expectations that this workforce will be able to administer these medications. When they cannot the family and or carers can feel burdened or overwhelmed in having to either administer the medications themselves or in having to engage other health practitioners.

Others reported that there are different clinical risk and model of care approaches to administering medications and escalation pathways into hospital settings based on the service provider. One stakeholder mentioned that improved consistency in approach and policy across service providers may assist both workforce and community expectations.

Key Finding 15: Workforce models in community settings need to consider scope of practice restrictions, particularly in relation to the administration of breakthrough medications and the clinical risk associated with safe care.

It is noted that this may be managed differently depending on the community service provider, and the communication regarding this with the primary carer and family may be important in expectation management including whether the consumer is able to die at home with adequate clinical support, if this is their preference.

4.3 Staff travel and access

The requirement for the community based palliative care workforce to travel across the region was not raised by community specialist palliative care service providers (through Karuna, St Vincent's or Metro North HHS) as a key barrier to providing care. It is expected that travel to more regional parts of the Brisbane North PHN footprint around Kilcoy and Woodford may create challenges for the palliative and end-of-life care workforce.

Some staff reported having a lack of equipment and support to deliver services, especially in more regional parts of the catchment, and for consumers with specific needs. (58) This was noted in relation to dressings and wound care, and in some cases availability of end-of-life medications at community pharmacies.

4.4 Funding models

Service providers report that palliative care funding remains insufficient and fragmented, contributing to structural barriers in communication, information sharing, and service integration. (7) (84) Existing funding models are siloed and do not support smooth transitions between settings or funding streams, including NDIS and aged care, while the absence of palliative care–specific MBS items can limit primary care delivery. (58) Community-based and population-specific approaches require dedicated investment. In particular, palliative paediatric services face ongoing funding insecurity, impacting staff retention. (1)

In the 2022/23 financial year across Brisbane North PHN there were 761.2 MBS palliative care related specialist services provided per 100,000 population, compared to 356.1 statewide and 255 nationally. (19) The rates of palliative care related MBS services were specifically higher in people aged 35 years or older, with the biggest difference occurring in the over 75 years age group when compared to the state (6,012 compared with 2,481.2) (19) The key funding sources for palliative care in the Brisbane North PHN region are the MBS, PBS, My Aged Care and DVA. (66) The Queensland Government continues to commit additional investment to support the growing demand for palliative care, committing an additional $171 million to specialist palliative care reform from 2021-22 to 2025-26. (90)

Stakeholders reported that both aged care and NDIS supports are not designed to suit the nuances of palliative care in which circumstances and needs can change rapidly. Palliative patients do not get prioritised when seeking increases or changes to their support scheme despite the often time-sensitive nature of their condition and needs. New aged care reforms which take effect from 1 November 2025, are designed to enable rapid access to increased funds when a patient does become palliative, with detail on this provided above.

It is also important to consider individuals under 65 with life-limiting conditions who are not children. These individuals may fall between NDIS and aged care supports, with limited home-based services availability, creating gaps in access to appropriate palliative care. (53) Service providers

Aged care reforms, which commenced on 1st November 2025 (101; 102; 103)

From 1 November 2025, a number of aged care reforms took effect under the Support At Home Program (which replaced the Home Care Packages Program and Short-Term Restorative Care Program). Within these reforms, there are key changes aimed at specifically supporting palliative and end-of-life care. These include:

- A new **end-of-life pathway** for participants who have been determined as having 3 months or less to live by a medical practitioner or nurse practitioner. This will provide immediate access to $25,000 which can be spent on non-specialist palliative and end-of-life care services over a 12 week period (which can be extended to 16 weeks if required). It is designed to support older people to remain at home for their end-of-life care if that is their preference. It will also allow for a high priority Support Plan Review to access the end-of-life pathway;
- A **Statement of Rights** for older people accessing aged care services which will seek to ensure a consumer choices and preferences are respected, and includes specific provision in relation to a right to equitable access to palliative care and end-of-life care for all people using and seeking Commonwealth funded aged care; and
- Strengthened provisions in relation to **outcomes for service providers** who provide palliative and end-of-life care. This will for example require service providers to ensure that medicines for pain and symptoms are prescribed, administered, reviewed and available 24 hours per day.

Service providers and stakeholders made reference to these changes in consultation, with some concerns raised about how these will work in practice. However, it is also acknowledged that the current delays in being able to access immediate funding may be addressed through the high priority review and the introduction of the end-of-life pathway which is likely to improve current arrangements.

continued to raise concerns surrounding the lack of formal support services and funding available to this cohort who often are left with no support.

> *Between 21 and 65, unless you've got motor-neuron disease and a NDIS package it can be really tricky to get funding." –* Service provider

Service providers also emphasised that there is insufficient funding to facilitate dying at home. Only 11 per cent of the national palliative care workforce report feeling adequately funded to deliver care at home, and general practitioners often face significant income and logistical challenges when providing home visits or complex palliative care consultations. (90) They also report that palliative care funding approvals take too long to be approved, with the person often dying before funding packages are approved. Home-based care involves long consultations, complex clinical issues, and coordination across multiple family members and carers, further straining primary care capacity.

Karuna, who receive funding to provide a free community-based palliative and end-of-life care service noted that they receive some government and philanthropic funding but estimate that notwithstanding workforce challenges, the service demand would allow them to expand to three times their current size if further funding were provided to support specialist palliative care in the community.

This insufficient funding in combination with a lack of workforce availability means that in most cases there is not the appropriate care available at home, requiring people to seek hospital care, particularly at end-of-life stages, and usually against their wishes. Service providers and carers reported that where dying has been facilitated at home it has usually been funded as a private out-of-pocket expense by the family.

> *"As far as people being able to die at home, we need more people on the ground who can help people stay at home. This might include Nurse Practitioners and Registered Nurses who can support the end-of-life stage and who are able to provide breakthrough pain relief." – Palliative Care Service Provider*

It is noted that services provided in a public or private hospital setting are funded as part of existing public and private hospital contracting arrangements on the basis of activity- volume and price based arrangements. This contrasts with community services which are typically block funded and often capacity constrained, which entrenches the acute palliative model (particularly at end-of-life stages).

Key Finding 16: Funding models do not support those over 18 years and under 65 years to receive community based palliative care, and often rely on family and carer support, adding financial pressure to families.

Key Finding 17: Financial and funding gaps also exist for those over 65 who are not on aged care packages, refuges and non-Australian residents.

Key Finding 18: For those consumers who currently receive either disability (NDIS) or aged care packages, there is a significant delay of 3-6 months in the approval to upgrade the package to include palliative care, This impacts on funding available to service providers. It is noted the aged care changes taking effect from 1 November 2025 may assist in addressing these delays.

Funding arrangements across Australia do not support timely community and home-based palliative and end-of-life care for adults. Recent changes to the aged care arrangements may assist for those aged over 65 years (and over 50 years for First Nations Australians) into the future, but overall this funding gap was seen to be leading to more hospital based palliative care and end-of-life care as care needs can often not be met in the community setting due to financial costs.

4.5 Limitations in specialist services

Specialist palliative care services face significant limitations in accessibility and equity. Not only is there a significant shortage of specialists limiting capacity, but these services are also concentrated in metropolitan inpatient settings, leaving community, home, and residential aged care homes under-served. (4) (7)

Stakeholders noted that paediatric palliative care in Queensland is city-centric, contributing to inequitable access. This can also create further travel and access issues for consumers and their families when they are required to travel large distances from their home to support palliative care, including in a hospice environment.

Populations such as people experiencing homelessness who are palliative facing particularly low equity of access to specialist services. (12)

4.6 Referral pathways and care coordination

Brisbane North PHN provide 19 palliative care clinical pathways through HealthPathways. This is useful in ensuring consistency in language and approaches and in detailing likely disease progression and trajectory, symptom control, anticipatory prescribing and pain management as well as referral across the Brisbane North PHN network. (91)

While this resource exists, improving palliative care requires stronger collaboration across the system with stakeholders reporting that the process of initially seeking out palliative care and being referred is confusing and lacks direction. Some health professionals are not aware of the clinical pathways available through HealthPathways. Many providers offer prolonged timeframes, such as 24 months, which doesn't meet the needs of a terminal diagnosis who has been told they have 12 weeks or less to live. There needs to be emotional sensitivity and flexibility surrounding planning both palliative care as well grief and bereavement support.

> *"My GP told my Mum she was palliative but that was all we got- we weren't sure what to do next. I just happened to find the palliative care information on the PHN website. I am not sure what our journey would have been if I didn't find that"* – Carer from within the region

Late referrals to palliative care can also limit the quality of care that can be provided during the end-of-life. As a society that is not death literate, carers and family may not be able to identify when they may need to initiate the process of seeking palliative care. There are added complexities due to the denial and grief surrounding the potential loss of a loved one. There is a need for education of carers to know how and when to ask for a referral.

Additionally, it is crucial for health professionals to ensure early referrals, where required, and be cautious of any potential signs of deterioration. Care is fragmented, in part due to the level of risk involved in the care of a palliative individual, and often no health professional wants to take on this burden and therefore leave it to the palliative care specialty. Other medical specialties often focus more heavily on a curative and restorative approach to care leading to delays in referrals to palliative care.

Part of any potentially high-risk care pathway such as oncology, should be an immediate referral to palliative care (where this is indicated) to start the journey if the patient wishes and be informed as required. Some medical specialties may be more reluctant to refer to palliative care due to their perception of medical failure, but this early referral is crucial. Many service providers report receiving too many late referrals which means by the time they see the individual it is often too late and the patient has deteriorated significantly. This can mean patients do not receive their comforts and wishes as they may have done if transitioned to the palliative care team earlier.

> *"Getting a timely referral for palliative care is really difficult. Particularly in oncology, they are really reluctant to refer to palliative care. Late referrals mean we don't have the chance to provide care and form those connections."* –
> Service provider

There are some examples of effective coordination between community and hospital based palliative care service providers. Communication is integral to these relationships, as is transparency surrounding patient status and understanding of responsibility within a shared patient care team. There are reports of some 'gatekeeping of patients' across the services with providers reluctant to collaborate.

There is also a lack of continuity of care following death which creates a significant burden on the family and carers. Families and carers often do not want to contemplate funeral arrangements and therefore it is crucial for healthcare providers to have the information and capability to provide that avenue for information when they are ready personally.

Often, to avoid commercial bias or through lack of death care awareness, service providers do not provide this information or referral to funeral providers, death doulas or provide any information about the rights and choices for families in terms of death arrangements and it is left up to families to initiate this process. This can mean there is a lack of connection and communication between family wishes and the funeral home during a critical period. The implementation of a warm handover between the care provider and the funeral home would facilitate a comfortable transition and ensure the wishes of the individual and family are understood and facilitated.

> *"Health care can refer to all other professionals but when a person dies and families are at their most vulnerable, they can't refer them on for support."* – Service provider

National Palliative Care Projects, Palliative Care Australia, and its member organisations support sharing innovation, strengthening evidence, and promoting best practice. Closer collaboration between general practice and state/territory health services, alongside enhanced cross-jurisdictional information sharing, can improve care consistency, streamline referrals, and support equitable access for patients moving between regions. (58)

For the last 10 years, Brisbane North PHN have hosted the Brisbane North Palliative Care Collaborative (BNPCC). The BNPCC is a group of stakeholders meeting to improve the palliative care journey for people in the North Brisbane and Moreton Bay region by facilitating stakeholder representative networking, information exchange, and shared learning. The group has shown improve familiarity and networking among providers operating in the region over the last four years.

4.7 The medical model

Palliative care research from Australia suggests that the medical model of palliative and end-of life care can lead to some negative experiences. While health professionals in Australia are not required to take the Hippocratic Oath, the principles in relation to good medical practice and codes of ethics centre around doing no harm, acting in the patient's best interest and prolonging life.

This can lead to overtreatment at end-of-life stages, late referral into palliative and end-of-life care and unnecessary prolonging of death which can impact on the quality of the death and dying experience for the consumer and their family and chosen carers.

Further concerns with the medical model include fear of litigation and concerns that health professionals must manage death. These circumstances may improve with increased palliative care experience and death literacy amongst health professionals, and consumer-led models which draw on a wider workforce and community approaches to supporting a positive end-of-life experience. (92)

Key Finding 19: Referral into hospitals for end-of-life care often occurs due to end -of-life medication needs, inadequate funding to support personal care at the end-of-life, and other clinical and socio-economic complexities.

Finding 20: Referral pathways between key service providers within Brisbane's north are reported as inconsistent and reliant on existing relationships and knowledge.

Finding 21: Early referral to palliative care is often impeded by health professionals' reluctance, which may stem from a perception of medical failure.

Referral pathways into the palliative care system are important to providing consumers and families with access to the North Brisbane and Moreton Bay network of service providers, noting that most consumers are not aware of what is available prior to needing palliative and end-of-life care. GP pathways into this network need strengthening and health practitioner education is needed to ensure earlier referral into palliative care services and to facilitate more open discussion around end-of-life.

Once referred into palliative and end-of-life care services people report a more positive experience, but referral within this service is heavily reliant on the existing relationships and knowledge of the service provider.

5. Health service utilisation and barriers

This section describes key barriers and enablers to palliative and end-of-life care from a consumer, carer and family perspective.

5.1 Demand growth and service shortages

Delayed access to specialist palliative care is a major issue in Australia. On average, individuals receive specialist palliative care for the first time only 15 days before death, despite evidence that care is beneficial from the point of diagnosis of a life-limiting illness. (53) Each day, around 400 people die from such conditions, yet over 62 per cent never receive palliative care. It is estimated that 50–90 per cent of the 160,000 annual deaths in Australia would benefit from palliative care, but many do not receive care that aligns with their needs or preferences. (53)

Demand for palliative care is increasing in line with Australia's ageing population. Around 80 per cent of deaths occur in people over 65, and by 2066 it is projected that 25 per cent of the population will be over 65. (7) In Queensland, the population aged 65+ grew by 47.1 per cent in the decade to 2016, exceeding the national growth rate. (7) Concurrently, the number of people accessing palliative medicine specialist services through the Medicare Benefits Schedule increased by nearly 85 per cent over the five years to 2015–16. In the Brisbane North PHN catchment, admitted palliative care accounted for 3.5 per cent and non-admitted care for 1.3 per cent of total health expenditure in 2022–23. Palliative care-related hospitalisations are rising faster than overall hospitalisations, increasing by 23 per cent over five years to 2020–21 compared with a 12 per cent overall increase in general hospitalisations. (93) There is a significant gap between the increasing need for palliative care and the availability of timely, accessible services.

As of 1 October 2025, there are 38 projects (excluding PHN activities) relating to palliative care to promote access to people living and/or working in the Brisbane North PHN region. (57)

- 13 projects targeting consumers, carers and community
- 19 projects targeting hospital-based clinicians;
- 21 projects targeting General practice-based clinicians
- 19 projects targeting aged care workforce
- 19 projects targeting community-based clinicians
- 11 projects targeting clinical students
- 9 projects focusing on underserved populations (priority populations).

Amongst this growing demand, there continues to be a heavy burden of intake and assessment, timeframes: waiting for My Aged Care funding, NDIS or a community access point. The current systems are not designed to suit the needs of all palliative clients and the pace and nature of progression of palliation. As waitlists continue to grow, this can often lead to difficult decisions around triaging and prioritising certain end-of-life care over other palliative patients.

> *"We just don't have any way of funding personal care workers for adults under 65 years."*– Service provider

Key Finding 22: There is evidence of delays in being able to access palliative care services. This is due to various factors including assessment and intake processes to receive palliative care funding, lack of awareness and navigation issues, and service capacity.

Key Finding 23: Stakeholders and consumers reported a preference to access a single, reliable and complete source of palliative and end -of-life care information and service available within the North Brisbane and Moreton Bay region.

Finding 24: Gaps in health professional communication and handover can lead to confusion, stress and an additional carer burden for end-of-life consumers and their families.

While service navigation resources and handover are improving, stakeholder feedback from consultation suggests more work needs to be done to build awareness in relation to service navigation and to improve handover between services.

5.2 Service navigation

People requiring palliative care often transition between multiple settings, making seamless coordination essential. (82) Communication between providers, patients, families, and carers is crucial to support individuals throughout their care journey. Under-served populations frequently lack understanding of palliative care, its benefits, and available services, while recognition of need may be complicated by diagnostic “overshadowing” or competing urgent health and social priorities. (58)

Standard practices, such as automatic referral at diagnosis of a life-limiting illness and a “no wrong door” approach across care settings, can help ensure early access and smooth transitions. (58) A consumer-centred approach to service integration also helps providers to try and understand the needs of priority populations and supports community awareness of palliative care and advance care planning.

Consumers and carers reported a lack of awareness of available services and resources, and a desire to access a single reliable and complete source of palliative and end-of-life services within the region. Most consumers and carers were not aware of, or directed to, the resources that are already provided by Brisbane North PHN. Service providers were more aware of the available resources and projects usually due to their linkage through the Brisbane North Palliative Care Collaborative, but this does suggest that improved marketing and awareness of the work that has been progressed needs to occur.

> *“I think communication is so important to stop people bouncing back in and out of hospital.”*– Service provider

Service providers and consumers provided examples of where primary care services (particularly pharmacists and GPs) question medications that may be prescribed through the specialist palliative care services provided in public and private hospitals, and that this causes distress usually for the primary carer who may not know whether the prescribed medication is suitable, and or who may be questioned in relation to morphine or opioid drug addiction. This does suggest that handover processes particularly between palliative care units in hospitals and with the consumer’s GP and pharmacists are really important where palliative and end-of-life care are being supported at home.

5.3 Travel and access (consumer and family)

Accessing palliative care can be challenging for patients and families due to travel distances, limited transportation options, and associated costs, particularly for those outside of metro areas. Patients living in socioeconomically disadvantaged or remote regions often face longer travel distances and additional burdens, which are compounded for priority cohorts with complex health or social needs, or those seeking culturally safe and supportive environments. (94) These travel demands increase the physical, emotional, and financial strain on both patients and carers, particularly when frequent appointments or home visits are required. Enhancing local service availability, providing transport support, and integrating telehealth can help reduce these barriers and ensure timely, equitable access to palliative care.

Access can also be made more difficult by the burden of symptoms. Service providers noted that for some, their pain and symptoms are too burdensome to seek out palliative care services. This highlights the importance of home-based care for those who are experiencing a significant symptom burden and who find travel difficult.

Sourcing a regular GP is also reportedly difficult for many. Due to the shifts in modern primary care and limited appointment availability, it is common for individuals to see multiple different GPs over time. This limits connection and understanding of patient history thus making it more difficult to monitor deterioration and the need for a referral to palliative care. This can also hinder GPs from being able to initiate difficult conversations surrounding death and ACP, meaning referrals may be left too late. Service providers did highlight that this can be less of a problem in less metropolitan areas where the community GP is more likely to see patients regularly and establish strong connections. However, in rural areas, access is once again limited.

> *“In this area, having a regular GP is impossible. They rely on the public health system.”*– Service provider

Key Finding 25: Travel demands increase the physical, emotional and financial strain on both patients and carers, particularly when frequent appointments are required.

This suggests that community based palliative care needs to be better supported through home-based consultations and services, and while community palliative care service providers are providing care in people’s homes, GPs and other medical professionals do not frequently provide home visiting services, largely due to costs.

5.4 Cost (out-of-pocket costs)

Cost is a significant barrier to accessing palliative care, largely driven by supply-side factors such as inadequate Medicare Benefits Schedule (MBS) funding, which can reduce GP and primary care engagement in providing palliative services. (53) Improved MBS payments and targeted schemes are needed to support community-based palliative care and facilitate ageing at home. Medication costs are also a concern, with shortages contributing to higher out-of-pocket expenses. For those requiring residential aged care, placement costs can further limit access. (53) Individuals under 65 who need palliative care are particularly disadvantaged, often shouldering costs themselves as they fall between eligibility criteria for the NDIS and aged care support. (53)

Sourcing consumables such as wound care or equipment within the home can pose a significant challenge for the care team. These items are often not covered by Medicare and thus become a regular, expensive out-of-pocket expense. While there are some programs designed to address need, such as the Medical Aid Subsidy Scheme which run continence aids, oxygen, and palliative care equipment programs, these have time limits and access criteria and are not available to everyone.

Within fee-for-service models of care provision, there are typically three cohort groups: a My Aged Care participant, NDIS participants or those who are independently able to afford the costs associated with care. It may also cover those with private health insurance, depending on the individual's cover and included services. This leaves a significant proportion of the region who are unable to access the care they need and are limited to not-for-profit organisations.

> *"Often low-income families have to make decisions about not taking medication because of the cost."*–
> Service provider

Key Finding 26: The financial cost burden is a significant barrier in accessing home-based palliative and end-of-life services, including medication costs, equipment and dressing costs, and personal carer workforce costs.

This finding suggests inequity in health access and options, with those of lower socio-economic status less likely to be able to receive palliative and end-of-life care at home.

5.5 Understanding of the practical needs of consumers wishing to die at home

A further challenge noted, was that families and carers may wish to support their loved one dying at home, but are not prepared for the reality of this in terms of personal care requirements, symptom and medication management, home modifications, management of clinical risks or concerns (which may be caused by other health conditions), and financial costs.

> *"Better education needs to be provided to carers and families about what supporting their loved on dying at home will mean in reality."* – Palliative Care Service Provider

5.6 Stigma and discrimination

Stigma, discrimination, and fear significantly impede access to palliative care. Individuals from marginalised or priority populations—including culturally and linguistically diverse communities, LGBTIQA+ people, and those experiencing homelessness—may avoid services due to unsafe or non-inclusive environments, fear of bias, or prior negative experiences. (58) Cultural differences in beliefs about dying, family decision-making, and care expectations can compound these fears if services are not culturally competent. (58) Addressing these barriers requires culturally competent, inclusive, and trauma-informed care, supported by staff education and supportive policies, to ensure services are safe, respectful, and responsive to the diverse needs of all patients.

Discrimination towards atypical family models is common and can lead to fragmented communication and suboptimal care. Where family is not a blood relative or direct relative, exclusion may occur. This can lead to significant disadvantage for vulnerable populations who often have a non-traditional familial structure. It is important for palliative care services to be flexible to the needs of their consumers and understand that often these individuals have a complex network of support. Particularly in Australia, with a significant migrant society, it is essential to be accepting of all family models and support networks.

> *"The fact that I was not a blood relative definitely led to some exclusionary behaviour even though I was listed as next of kin."*–
> Service provider and carer

There is significant stigma and false perception surrounding the concept of palliative care and what it means. Many people associate it exclusively with imminent death or the withdrawal of treatment, rather than recognising its focus on improving quality of life, comfort, and support throughout the course of a life-limiting illness. This misconception can lead to fear, denial, and delayed referrals, preventing individuals and families from accessing the full benefits of palliative care early in their illness journey. Addressing these false perceptions through community education and clear communication from health professionals is essential to normalise palliative care as an integral part of holistic, person-centred healthcare. Perceptions that accessing palliative care is burdensome or drains government resources can also further discourage engagement. (58)

5.7 Safeguarding for vulnerable consumers

Protecting the rights of vulnerable patients is also a fundamental aspect of quality palliative and end-of-life care. Older people, particularly those who are frail, cognitively impaired, or socially isolated, may be at heightened risk of neglect, exploitation, or elder abuse—whether financial, emotional, or physical. In such cases, their ability to make informed choices or advocate for their own needs can be compromised.

Ensuring that consumer rights are upheld requires strong safeguarding mechanisms, clear communication, and proactive identification of risk factors by healthcare professionals. Embedding principles of dignity, autonomy, and consent within all care interactions is essential, along with training staff on safeguarding. Elder abuse can co-occur with cognitive impairment which can create complex legal, clinical and financial situations at end-of-life stages.

A rights-based approach ensures that even the most vulnerable individuals are protected, respected, and supported to receive care that aligns with their values and wishes.

5.8 Availability and access to medications

Access to essential palliative care medicines remains a critical challenge. PBS data for 2022–23 showed that the Brisbane North PHN region had lower rates of prescriptions and people receiving prescriptions compared to the Queensland average, though rates were closer to the Australian average (Brisbane North PHN 5,258.9 per 100,000 persons, Queensland 5,712.4, Australia 5,138.7). (95)

The most notable gap was in pain relief prescriptions, where Brisbane North recorded substantially fewer people accessing medications and fewer prescriptions overall than the state average(4,016 compared with 4,463.1 per 100,000 persons). (95)

This aligns with ongoing shortages of key palliative care medicines, including opioids and analgesics, which have led clinicians to prescribe less effective alternatives and caused avoidable hospital admissions. The withdrawal of suppliers such as Ordine morphine oral liquid has been particularly disruptive, with frequent medication changes creating confusion, errors, and suboptimal care. (53)

Families and carers are left to source alternatives at considerable cost, with some medicines costing up to $100 per bottle without PBS subsidy or 23 times more when imported from overseas. (53) These shortages not only increase financial stress but also erode continuity and quality of care. Recent proposals to address these systemic issues have included expanding PBS coverage for palliative medicines, stockpiling and better monitoring of supply, reducing co-payments, and incentivising local manufacturing of critical drugs.

Such reforms will be vital to ensure timely, affordable, and equitable access to essential medications for people requiring palliative care. Under a PHN project, 41 pharmacies in the region committed to stock the national palliative care medicines (or the Queensland core palliative care medicines for pharmacies that signed up before May 2024) in the last twelve months. (57)

The cost of palliative medications is already significant. There is the added complexity of how rapidly symptoms and thus medication needs can change. This can often lead to wasted costs on medication that individuals no longer require as well as an increased burden on the carer in seeking and filling updated scripts.

Access to palliative medications varies between community pharmacists with some being more flexible and accepting of the inherent variability of these medications whilst others are more reluctant. Some pharmacies are also less willing to fill scripts due to the high rates of drug misuse as well as stock issues. Community palliative care service providers emphasised the importance of developing relationships with community palliative care friendly pharmacists to ensure consistency and appropriate access when needed.

"I encourage our patients to have a good GP and community pharmacist. That makes a big difference in their care and ability to access care quickly."– Service provider.

Key Finding 27: Access to palliative medications in the community has been a previously identified barrier to home based palliative care. Brisbane North PHN have sought to strengthen access to palliative medications in the community through the targeted and active commitment of selected community pharmacists to stock medications to ensure timely access for consumers.

Brisbane North PHN: Palliative Care in Community Pharmacy Project (107)

The Brisbane North PHN's **Palliative Care in Community Pharmacy Action Plan** was a strategic initiative developed under the Australian Government's Greater Choice for At Home Palliative Care measure. The primary goal of the project is to increase the capacity and capability of community pharmacists within the North Brisbane and Moreton Bay region to support safe, quality palliative care for consumers who wish to receive care and die at home. This is in response to identified barriers, most notably the lack of timely access to necessary palliative care medicines in the community, and the need for greater support and integration of pharmacists into the palliative care team.

This has included a number of key action areas including:

- **List of Palliative Friendly Pharmacies.** The goal of this has been to improve timely access to medicines in the community by increasing the visibility of pharmacies that stock palliative care medicines for prescribers and other pharmacies.
- **Consumer Resources.** The goal of this has been ensuring consumers have easily accessible, detailed information about palliative care, including medicines and support services.
- **Pharmacy Campaign.** This has aimed to improve the knowledge, skills and confidence of community pharmacists and improve medication acers and support for consumers.
- **Prescriber Engagement.** This has sought to promote proactive prescriber behaviours (including GPs) and enhance communication between prescribers and community pharmacists.

Resources and tools for this and other projects are all provided on the Brisbane North PHN Palliative Care website.

Conclusion

This Palliative Care Needs Assessment Report shows that palliative and end-of-life care is an area of rapidly growing need across the region, with complex considerations which include the needs of priority cohort groups, and a need to reflect holistic, contemporary and consumer centred care models and settings. This will require services across the region to be well planned and funded into the future.

Whilst a small but strong network of dedicated, passionate service providers exist within the region, there remains a need to improve awareness and access to services, strengthen referral pathways, and provide education to the broader community and health workforce about palliative and end-of-life care. These obligations do not just sit with health professionals, noting that a Compassionate Communities approach that improves death literacy and conversations across the North Brisbane and Moreton Bay community would help in holding space for death and dying conversations, providing holistic models of care, supporting those in palliative and end-of-life stages, and in supporting those who are grieving.

The 27 findings across this Report lend themselves to the following key recommendations to strengthen existing services and experiences and address systemic gaps.

- **Exploring the viability of an adult hospice for the region and improving access to home-based models of care.** The gap between consumer preferences to receive palliative care and die at home or in a community setting, and what occurs in practice are significant with the region having a higher hospitalisation rate for palliative care than both the Queensland and Australian average. As well as not meeting consumer preferences, this hospital-based care adds financial costs to the palliative care service delivery model for the region. This suggests work could be undertaken within the region to improve the funding, funding access and support provided for consumers who wish to die at home or in an adult hospice setting- and reduce unnecessary hospital admission.
- **Improving education and training in relation to priority cohort palliative care and end-of-life needs.** This Report identifies significant complexity in relation to priority cohort groups and palliative and end-of-life care. Education and training of the health and wider workforce needs to be strengthened to enable culturally safe, trauma informed and nuanced care. In addition, tailored models of care need to be developed to provide consumer access to wider community supports including peak bodies, religious or cultural leaders or Elders, and processes and rituals which support a positive experience. Of particular note from stakeholders across the region is the need to develop a model of care for those who are socially isolated and /or who do not have family or carers at their end-of-life stage. This model of care may be suited to death doulas who can provide additional support to existing services for quality holistic care.
- **Enhancing contemporary and consumer led models of care.** Palliative and end-of-life care have been a medically led process, and there is a need both within the region and across Australia to adopt more holistic approaches to palliative and end-of-life care which better include spiritual care, trauma support, death literacy and addressing fears of dying, choice and control (including advance care planning and VAD) and death planning, and are inclusive of emerging roles including grief and bereavement counsellors and death doulas.
- **Improving death literacy and enabling a Compassionate Communities approach including promoting awareness of extensive place-based resources in relation to palliative care.** A very strong theme through consultation in the region has been the need to improve death literacy at a community level and strengthen the naturally occurring networks through the existing passionate palliative care workforce and community partners to enable Compassionate Communities across the North Brisbane and Moreton Bay region.
- **Consideration of a palliative care digital front door for the region.** Consumer awareness of palliative care resources and tools remains low. A digital front door may be a means to improve access to services and promote awareness of the extensive place-based resources in relation to palliative care.
- **Improving data collection:** There were significant limitations in region specific palliative care data. Into the future, better data collection including around the journey of consumers through the palliative and end-of-life care system, will help to inform service planning, utilisation and access rates across the region. Capturing service data on priority cohort groups and needs, as well as the settings in which people die across the region may also help in informing current practices and improvements needed in models of care to support culturally responsive, trauma informed and consumer focused care.

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Appendix A: List of stakeholders consulted

Aboriginal and Torres Strait Islander Community Health Service (ATSICHS)- Palliative Care projects

Advance Care Planning Australia

Aged and Disability Advocates Australia

Blue Care & Hummingbird House

Caboolture Hospital (MNHHS)

Carers Queensland

Consumers and carers

Cornerstone Funerals

CPL Choice, Passion, Life

Ethnic Communities Council of Queensland

Focused Healthcare

Holistic End-of-life & Death Care Australia

Institute for Urban Indigenous Health

Karuna Hospice Service

Karuna Hospice Services

Karuna Hospice Services Carer Program

McArthur Community Care

Metro North First Nations Leadership team

Metro North Palliative Care Grief and Bereavement Service (MNHHS)

MICAH

Ozcare

Palliative Care Queensland

Queensland Ambulance Service

Queensland Council LGBTI health

Queensland Positive People

Queenslanders with Disability Network

QVAD Support and Pharmacy Service

Redcliffe Hospital (MNHHS)

Regis Caboolture

St Vincent's Private Hospital Brisbane

Undertaking Grace