Palliative Care

Needs Assessment

Informing commissioning and projects
for the North Westerm Melbourne Primary
Health Network region.

December 2025

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Acknowledgements

North Western Melbourne Primary Health Network (NWMPHN) acknowledges the peoples of the Kulin nation as the Traditional Custodians of the land on which our work in the community tales place.

We pay respect to their Elders past and present. We also recognise, respect, and affirm the central role played in our work by people with lived experience, their families and carers.

Contributors

We gratefully acknowledge the contributions of all the individuals who participated in this project, and we particularly extend our thanks to the numerous health providers, community groups, and associations that have played a vital role in making this work possible. Their support is instrumental in enhancing our understanding of health needs within the NWMPHN region.

Disclaimer

While the Australian Government Department of Health, Disability and Ageing (DHDA) has contributed to the funding of this material, the information contained in it does not necessarily reflect the views of the Australian Government and is not advice that is provided, or information that is endorsed, by the Australian Government. The Australian Government is not responsible in negligence or otherwise for any injury, loss or damage however arising from the use of or reliance on the information provided herein.

This report was developed by NWMPHN in line with the DHDA's Palliative Care Needs Assessment Guidelines (2025) and DHDA's PHN Needs Assessment reporting requirements.

About this report

This report presents the key findings of the North Western Melbourne Primary Health Network (NWMPHN) Palliative Care Needs Assessment (PCNA) which provides a comprehensive analysis of palliative care needs across the NWMPHN region. These insights will inform evidence-based decision-making for activities within NWMPHN's Greater Choice for At Home Palliative Care (GCfAHPC) program, funded by the Australian Government Department of Health, Disability and Ageing (DHDA).

Spanning approximately 3,212 square kilometres, from Darebin in the inner east to beyond Bacchus Marsh in the west, and from the Western Treatment Plant north to Lancefield, the NWMPHN region is one of Victoria's fastest growing and most diverse areas. It comprises 13 local government areas. By 2030, its population is projected to grow by more than 12 per cent, reaching nearly 2.3 million people, within a landscape characterised by significant socioeconomic advantage and marked disadvantage.

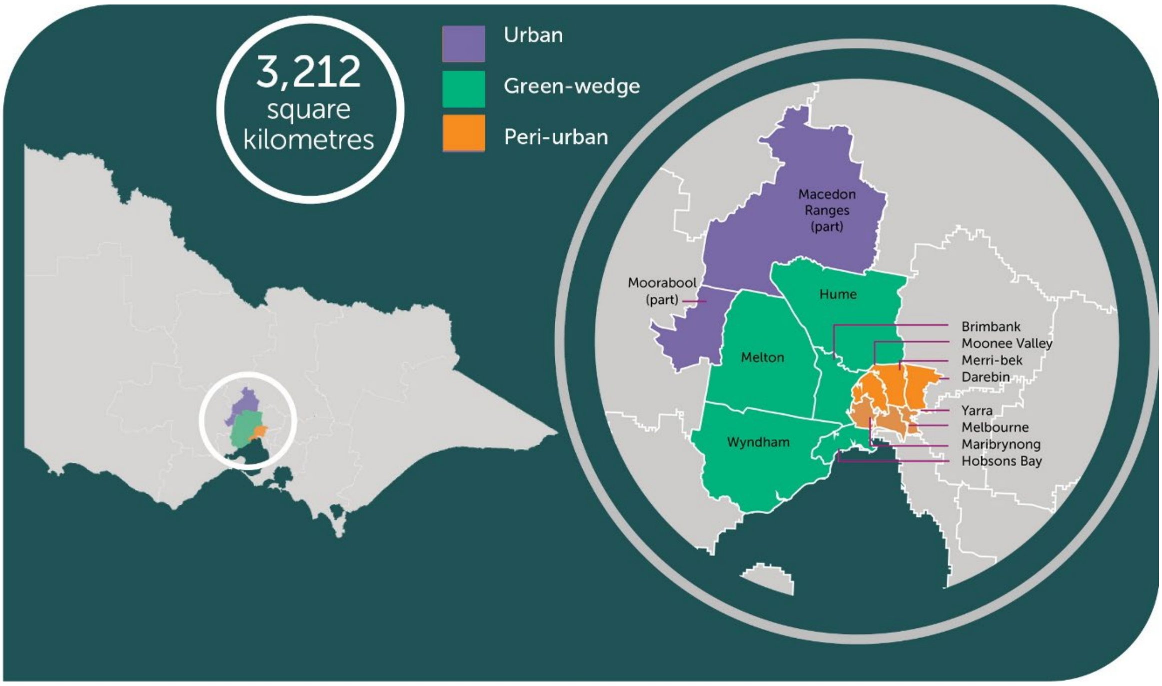
NWMPHN's role in palliative care

NWMPHN receives Commonwealth funding to deliver the GCfAHPC program. Many people nearing the end of life prefer to be cared for and to die at home, and this initiative strengthens palliative care coordination and integration to support that choice. The program aims to improve the quality of care and support for people with known life-limiting conditions by enhancing access, continuity, and clarity of care in the home setting.

To achieve this, NWMPHN provides education, resources, and initiatives that build capability in the primary care workforce, improve integration and coordination between primary care and specialist palliative care providers, and promote awareness of end-of-life options within the community.

The PCNA is a key mechanism supporting the GCfAHPC program. It ensures that planning and implementation activities are grounded in local evidence and aligned with the needs of the communities NWMPHN serves. Voluntary assisted dying (VAD) and palliative care are distinct but complementary approaches to end-of-life care. VAD activities within the program must be non-clinical and non-service delivery in nature.

Figure 1. North Western Melbourne Primary Health Network (NWMPHN) region showing local government areas (LGAs).



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Statement of AI usage

The development of the PCNA included usage of NWMPHN-approved AI tools, namely Microsoft Copilot. Copilot supported the project across multiple steps of the methodology.

This was limited to lower-risk activities that were easily quality checked, such as brainstorming, synthesising, theming, and categorising input information. Copilot was not used in the first instance to search and identify literature, analyse quantitative data, or report findings, and it was only applied to outputs produced by the project team. These included internal reports, literature review matrices, summary findings, and qualitative frameworks.

Members of the project team evaluated the insights developed with the support of Copilot for quality and accuracy before reporting. The final text for this report was then subedited and crosschecked by NWMPHN’s communications team.

Acronyms

ABF	Activity-based funding
ABS	Australian Bureau of Statistics
ACP	Advance care planning
AHP	Allied health professional
AIHW	Australian Institute of Health and Welfare
CALD	Culturally and linguistically diverse
COM-B	Capability, Opportunity, Motivation – Behaviour model
COPD	Chronic obstructive pulmonary disease
DHDA	Department of Health, Disability and Ageing
DLI	Death Literacy Index
EAG	Expert advisory group
EMR	Electronic medical record
ERP	Estimated resident population
FTE	Full-time equivalent
GCfAHPC	Greater Choice for At Home Palliative Care
HNA	Health needs assessment
ICD-10-AM	International Classification of Diseases, Tenth Revision
IRSD	Index of Relative Socio-economic Disadvantage
LGA	Local Government Area
MBS	Medicare Benefits Schedule
MDT	Multidisciplinary team
NWMPHN	North Western Melbourne Primary Health Network
PACOP	Palliative Aged Care Outcomes Program
PBS	Pharmaceutical Benefits Scheme
PCAS	Victorian Palliative Care Advice Service
PCNA	Palliative Care Needs Assessment
PCOC	Palliative Care Outcomes Collaboration
PMS	Practice management system
POLAR	Population Level Analysis and Reporting
QI	Quality improvement
RACH	Residential aged care home
SME	Subject matter expert
TDF	Theoretical Domains Framework
VAD	Voluntary assisted dying

Key definitions

Community-based care	The provision of palliative care services in the community, recognising that people live in various types of homes including personal residences, owned or rented; residential aged care homes, retirement villages, and other communal living arrangements; mobile homes, caravans, cars and other locations as appropriate for people who are experiencing homelessness; correctional facilities, remand centres and detention centres; group homes and other specialist housing for people with a disability; and specialist accommodation for people experiencing severe mental illness.
Cultural competency	The set of behaviours, attitudes, and policies that come together to enable a system, agency, or professionals to work effectively in cross-cultural situations (AIHW, 2015).
Disability	A person is considered to have disability if they have any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for six months or more (ABS, 2022)
Generalist palliative care	Clinicians who care for people with life-limiting conditions as part of their usual scope of practice, including health professionals such as GPs, nurses, aged care staff and allied health professionals (AHPs) who incorporate palliative approaches into their usual care. They manage straightforward needs and coordinate with specialist services when complexity increases (Palliative Care Australia, 2022)
Index of Relative Socio-economic Disadvantage (IRSD)	The Index of Relative Socio-economic Disadvantage (IRSD) summarises 20 variables that directly or indirectly contribute to disadvantage in a particular geographic location. The Australian average IRSD score is 1000. IRSD is calculated for each Statistical Area 1 (SA1) in Australia, each of which generally has a population of between 200 and 800 people. A lower score indicates a higher level of disadvantage.
Palliative care	Palliative care is an approach that improves quality of life for people with life-limiting illness and their families through the prevention and relief of suffering by early identification, assessment and treatment of physical, psychosocial and spiritual needs. Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life (Palliative Care Australia, 2022)
Palliative care assessment	A comprehensive and person-centred evaluation to identify and address a patient's physical, psychological, social, and spiritual needs, as well as those of their family, when they have a life-limiting illness. The assessment is an ongoing process designed to relieve suffering, improve quality of life, and support the patient in living as fully as possible until death, often including symptom management and helping the family cope with the illness and bereavement.
Palliative medicine physician	Palliative medicine physicians are required to have completed three years of full-time equivalent training in either a paediatric or adult setting under the supervision of a palliative medicine physician. Successful trainees gain the qualification of Fellow of the Royal Australasian College of Physicians (FRACP), Fellowship of the Australasian Chapter of Palliative Medicine (FAChPM) and are accredited to practice as a palliative medicine physician in Australia or New Zealand (AIHW, 2025b)
Palliative care nurse	The classification of nurses in Australia varies with the type of training they have undertaken. Nurse practitioners, registered nurses and enrolled nurses need to complete a variety of short or more comprehensive courses (including postgraduate certificates and master's degrees) to work in the field of palliative care. Postgraduate qualifications are generally required for nurses working in specialist palliative care services (AIHW, 2025b)

Palliative Care Outcomes Collaboration (PCOC)	A national palliative care outcomes and benchmarking program, PCOC's primary objective is to systematically improve patient outcomes (including pain and symptom control) (PCOC UOW, 2020)
Person living with a life-limiting illness	Refers to a person with an illness where it is expected that death will be a direct consequence of the specified illness. Such illnesses include cancer, heart disease, chronic obstructive pulmonary disease, dementia, heart failure, neurodegenerative disease, chronic liver disease and renal disease. The term person living with a life-limiting illness also incorporates the concept that people are actively living with such illnesses, often for long period of time, not simply dying.
Potentially preventable hospitalisations	Hospital admissions for conditions that could have been avoided through timely and effective care in the community or primary health setting. They are used as an indicator of how well the health system provides accessible, preventive, and early treatment services (AIHW, 2023)
Social determinants of health	The social determinants of health are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems (WHO, n.d.)
Specialist palliative care	Refers to providers with formal training and multidisciplinary expertise in palliative care, including palliative medicine physicians and palliative care nurses who support people with complex needs and provide consultation, education and mentorship to generalist providers. Specialist palliative care can be provided in hospital and in the community (Palliative Care Australia, 2022)

Executive summary

NWMPHN's Palliative Care Needs Assessment (PCNA) provides a comprehensive analysis of the palliative care needs of people living in the NWMPHN region. Its purpose is to build an evidence-based understanding of how people with life-limiting illness, and their families, carers, and service providers experience care. It exists to identify gaps and opportunities to improve access, quality and equity across the region.

Context

This PCNA, conducted by NWMPHN in 2025, is an evidence-based assessment that defines, identifies, and measures palliative care needs of the region's population. It is designed to directly inform planning for the Greater Choice for At Home Palliative Care (GCfAHPC) program.

Underpinned by a robust methodology, the assessment draws on quantitative and qualitative analyses, guided by research questions aligned with the key factors influencing the quality and equity of at home palliative care. The involvement of primary care providers, including general practitioners and nurses, and subject matter experts, is integral to ensuring relevance and accuracy. This is most evident in Section 4, which builds on the social, cultural and economic factors outlined in Section 2 by incorporating rich local insights gained through stakeholder consultations. Together, these perspectives provide a nuanced understanding of the complex experiences and needs related to palliative care in the NWMPHN region.

The PCNA is informed by contemporary frameworks that emphasise early, concurrent and person-centred care delivered through coordinated partnerships between generalist and specialist services. Using these frameworks, the assessment applies a tiered model of care that acknowledges the different trajectories of illnesses to identify needs and service gaps across the continuum. In this context, "service gaps" refers to health system challenges, including supply and demand pressures, that limit the system's capacity to meet current and emerging health needs.

This report also incorporates insights from NWMPHN's 2025-28 region-wide Health Needs Assessment (HNA), conducted in 2024. Relevant findings have been integrated to highlight population growth and social determinants that shape health and wellbeing and influence palliative care needs.

Additionally, it builds on valuable insights gained from prior work under the GCfAHPC program at NWMPHN since 2018, including a quality improvement project and consultations with our Clinical and Community Councils and Older Adults Expert Advisory Group.

Method

A mixed-methods approach was used for this assessment, combining quantitative and qualitative data sources.

Comparative need was examined through analysis of quantitative population health data and targeted literature reviews. Felt and expressed need were identified through the views of primary health care professionals, primarily gathered through qualitative methods. Normative need was defined using insights from primary care professionals and NWMPHN subject matter experts (SMEs).

Comparative need analyses drew on a wide range of quantitative and qualitative sources to build an evidence-informed understanding of palliative care from multiple perspectives, including why it is a public health priority, how the system is structured and performing, and which population groups experience inequitable access. Epidemiological indicators analysed included population characteristics, socio-demographic profiles, and chronic disease prevalence.

Eight in-depth semi-structured interviews were conducted, including six with 14 primary care professionals involved in palliative care. Two interviews were conducted with NWMPHN SMEs from teams supporting primary care improvement and data capability. In addition, 32 responses were received to a death literacy index survey. An inductive approach was used to analyse qualitative data and identify emerging themes.

Practical opportunities for action were identified through triangulation of all sources and prioritised based on their feasibility.

Key findings

The PCNA provides an evidence-based understanding of how people with life-limiting illnesses, and their families, carers, and service providers, experience palliative care within the NWMPHN region.

The findings highlight gaps that may be driving unmet needs, and identify opportunities to improve access, quality and equity. The summary of key findings across core research questions is provided below.

Communication and awareness

Effective communication between health care providers, patients, families and carers emerged as a foundation of holistic and person-centred palliative care. It directly influences the ability of primary care professionals to deliver timely, continuous, and well-coordinated support, as well as shaping confidence and capability.

The analysis found that communication is most effective when it is honest and open, empathetic, and tailored to the needs of patients and their families or carers. However, primary care settings often operate under significant time and resource constraints, which limit opportunities to apply best practice communication approaches. These pressures are intensified by the inherent complexity of communication in palliative care contexts.

Strengthening communication through structured, culturally competent approaches may help in timely, empathetic conversations between providers, patients, and families, by offering awareness, providing practical resources, and initiatives to enable coordinated, person-centred care.

Knowledge and capability

Findings showed that opportunity and motivation frequently act as both barriers and enablers of effective palliative care delivery. Even when capability exists, limited opportunity, such as insufficient time, funding or resources, or low motivation, often tied to low confidence, can impede change.

This dynamic was particularly clear in the different barriers experienced by GPs and nurses, highlighting the need for tailored strategies that respond to specific behavioural drivers within each group.

Although knowledge and skill gaps were identified among primary care providers, these were largely shaped by physical opportunity constraints, especially time pressures and limited funding. These not only restrict opportunities for capability building but also contribute to emotional strain and reduce confidence in delivering holistic, patient-centred care.

Data and equity

The analysis identified two key systems, GP data gathered through Outcome Health's POLAR platform, and patient data collected through the eponymous PalCare system, as underutilised sources of insight. Current use of POLAR has strengthened the depth and usability of program-level data. However, additional work is needed to support program teams, including the GCfAHPC team, to use this more effectively for planning, equity analysis and service improvement.

The PalCare system was identified as having strong potential to provide valuable information about who is being referred to specialist palliative care, referral patterns, and key demographic and clinical characteristics such as age, diagnosis, care phase, and, where recorded, cultural or linguistic needs.

Internal SMEs identified a core set of information needs to better inform program design and service delivery. Several issues currently limit the ability to meet these needs across primary and specialist systems, including data completeness, accuracy, and consistency.

Future actions and directions

This PCNA identifies many opportunities to improve outcomes in palliative care across the NWMPHN region. While these may not necessarily be matters that NWMPHN will implement, they provide an essential framework to guide collaboration with stakeholders when planning and implementing activities in the GCfAHPC program.

The findings inform five priority focus areas.

1. Build primary care capability

This includes supporting primary care to utilise patient resources to prompt discussions about advance care planning (ACP) and palliative care. There are existing capability-building opportunities and resources that can be promoted, particularly those available in self-directed or flexible formats. Encouraging participation in low-resource, low-commitment peer learning and mentoring opportunities, such as communities of practice is another feasible opportunity.

Expected impact: Improvements in the timeliness and quality of palliative care conversations, increased uptake of evidence-based education and resources including accessible avenues for shared learning and professional support.

2. Enhance cultural competency

There is opportunity to support informed decisions about interpreter use among patients with life-limiting illnesses and limited English proficiency. Sharing culturally safe care education and resources is a logical first step.

Expected impact: Increased knowledge and awareness of optimal interpreter use and better communication and outcomes for culturally diverse and vulnerable population groups.

3. Improve communication, integration and adoption of digital health initiatives

The findings highlight areas for collaboration between primary and community palliative care services through improving communication, integration and adoption of digital health initiatives. This includes enhanced shared patient information to enable multidisciplinary care coordination. It also concerns supporting the uptake of palliative care e-referrals and increased use of My Health Record for document sharing (for example, through uploads of ACPs and patient summaries).

Expected impact: Improved communication between care providers, including timely referrals to specialist palliative care services and regular updates to primary care providers, facilitating continuity of care, prompt access to key information, and clear roles and responsibilities for all practitioners involved in a patient's care.

4. Increase community and primary care awareness

There is further work needed to build understanding of palliative care and ACP among health professionals and the community. Opportunities include delivering awareness-raising campaigns for community and primary care teams and promoting the availability of services.

Expected impact: Increased knowledge and awareness of palliative care and community death literacy. Increased usage of specialist advice and secondary consult services.

5. Use local data to monitor, evaluate and improve primary care programs

The assessment revealed opportunities to enhance existing priorities. These are also outlined in Victoria's end-of-life and palliative care frameworks, as well as the National Palliative Care Strategy.

This includes data-sharing with specialist community palliative care providers, primary care and Department of Health, Disability and Ageing funded programs such as PACOP and PCOC. As well as further explore opportunities to integrate available primary care datasets.

Expected impact: Enhanced data-driven planning in the GCfAHPC program.

1. Introduction

1. Introduction

1.1 Purpose and scope

The Palliative Care Needs Assessment (PCNA) was conducted by NWMPHN to build an evidence-based understanding of palliative care needs across the region. It explores how people with life-limiting illness, their families, carers, and service providers experience care, and it identifies gaps and opportunities to improve access, quality and equity.

Currently, many people engage with palliative care late in their illness, often in hospital settings and typically via specialist teams. This pattern reflects the historical delivery and funding of palliative care in acute settings, rather than in primary care. Strengthening workforce capacity, after-hours coverage and coordination across primary and community care will help shift access earlier and closer to home (DHDA, 2019; PCA, 2018).

Insights from the assessment inform regional planning, workforce capability, service coordination and quality-improvement activities. They also support Commonwealth reporting requirements and help support primary care to deliver timely, person-centred palliative care.

The assessment is guided by Palliative Care Australia's *Palliative Care Service Development Guidelines* (PCA, 2018) and the Victorian Department of Health's *End-of-life and palliative care framework* (DoH, 2016). Both emphasise early, concurrent and person-centred care delivered through coordinated partnerships between generalist and specialist services. Using these frameworks, a tiered model of care focused on illness trajectory (see **Figure 2**) has been applied to needs and service gaps across the continuum.

Figure 2. Tiered model of palliative care to support changing complexity of individual needs against workforce capability.

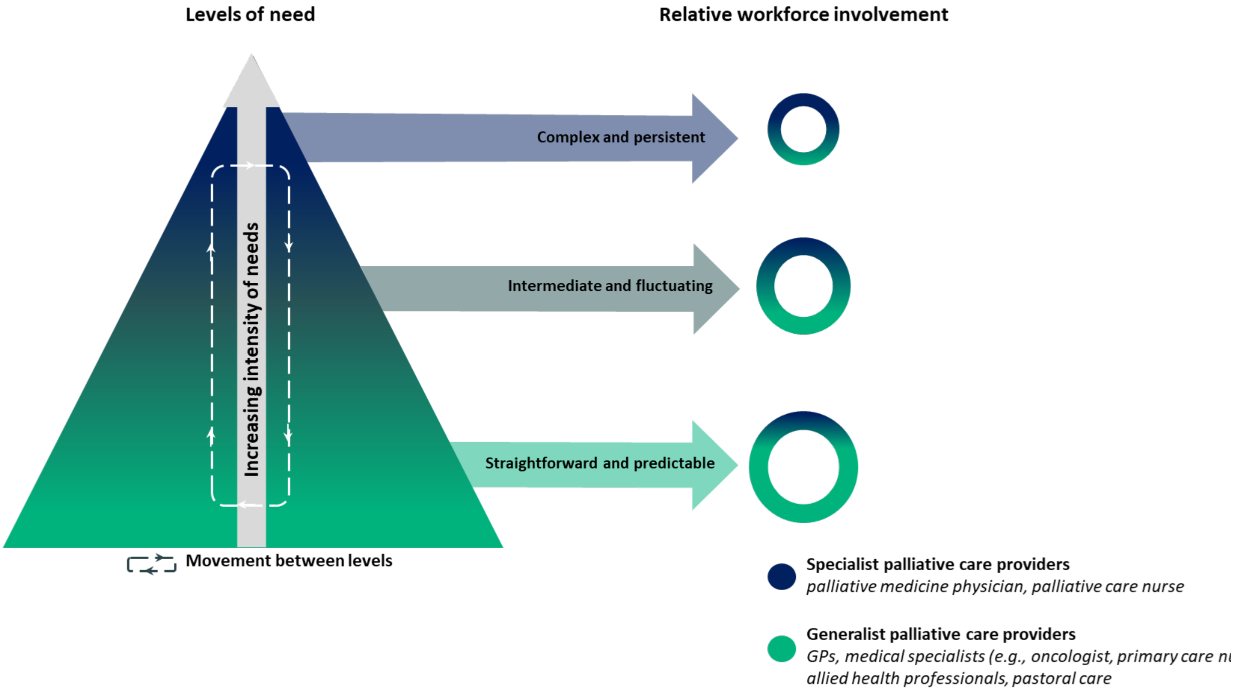

Figure note: Adapted from the *Palliative Care Service Development Guidelines* (PCA, 2018).

Objectives

The PCNA:

1. **Integrates evidence** from recent literature, population health datasets and stakeholder insights to develop a comprehensive understanding of palliative care needs.
2. **Collaborates with key stakeholders**, including SMEs and external primary care partners, to ensure findings reflect current service realities and diverse perspectives.
3. **Increases awareness** of palliative care needs, and identifies opportunities for continuous improvement, including processes to maintain and refresh data and insights.
4. **Enables action** by producing a practical resource to guide program-level planning, coordination, commissioning and primary care capability activities for people with a life-limiting illness and their families.

Research questions

To guide the assessment, three research questions were developed (**Figure 3**). These emerged from a rapid-literature review and thematic analysis using the DHDA focus areas (see **3.1 Research method** for detail).

Figure 3. Research questions

Communication and awareness: What are the communication preferences of patients with life-limiting illness and their relative/carers and how does the health provider awareness of these preferences influence the delivery of holistic palliative care across illness trajectories?

Knowledge and capability: What knowledge gaps, misconceptions and attitudinal barriers exist among GPs, practice nurses and practice teams, and what practical strategies could improve them?

Data and equity: What gaps and challenges in capturing cultural, linguistic, and diversity data limit palliative care planning, and what practical strategies can improve data quality, integration, and equity to support person-centred care?

1.2 Context

Palliative care supports dignity, comfort and choice. Yet most people who wish to die at home do not, and current hospital-centric models are unlikely to meet rising demand without stronger primary and community care integration and redesign.

Why palliative care is a public health priority

Australians are living longer with complex chronic conditions. Demand for timely, coordinated and compassionate palliative care is increasing. Approximately 160,000 deaths occur nationally each year, projected to rise to 200,000 by 2030. It is estimated that three-quarters could benefit from palliative care (PCA, 2018).

How the system is currently structured

Palliative care remains specialist-led and hospital-centric, reflecting workforce shortages, uneven service distribution and fragmented coordination (AIHW, 2025b; PCA, 2018). Yet a substantial share of need can be met by generalist palliative care in primary care and community-based settings, delivered by GPs, nurses, and allied health professionals (AHPs), with specialist service (community or hospital) input stepped up as complexity increases (AIHW, 2025b; DHDA, 2019; PCA, 2018). As shown in **Figure 4**, the tiered model and illness trajectory explains how needs and roles escalate.

Figure 4. Illness trajectory of life-limiting illnesses

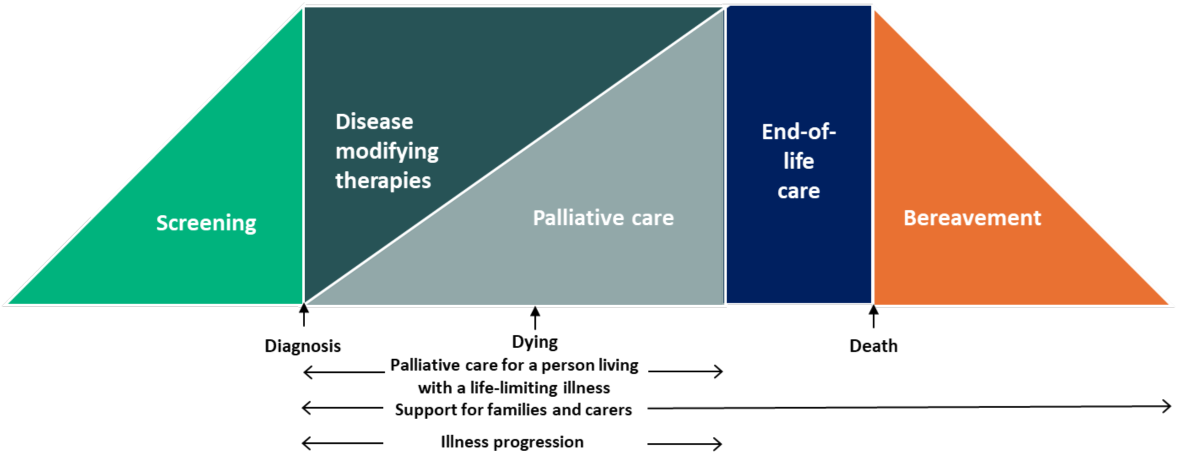

Figure note: Adapted from the *Palliative Care Service Development Guidelines* (PCA, 2018).

Preferences and place of death

Individual preferences, particularly care and death locations, are central to palliative and end-of-life care. Nationally, around 70 per cent of people say they would prefer to die at home, yet only about 14 per cent do so (AIHW, 2025b) [1]. This highlights gaps and challenges in aligning care with people's wishes, including timely referral, and the availability of home-based services. This also includes support for carers, who frequently report unmet needs for respite, training and emotional support.

Palliative care neither aims to end life nor to prolong it. Its purpose is to relieve suffering and support what matters to the person and their family. This means that while it is not at odds with voluntary assisted dying, neither are the two matters synonymous.

Since 2019, voluntary assisted dying (VAD) has been a small, regulated part of Victoria's end-of-life care system (accounting for less than one per cent of all deaths each year). It is often delivered in community settings and is framed around dignity, choice and control – the same values integral to palliative care. In 2024-25, among Victorians who died via administration of a VAD[2] substance, 48 per cent died at home (DoH, 2025). To better honour individual preferences, Victoria needs stronger primary-care led, community-based supports and clearer shared-care pathways so more people can receive coordinated care, and, when that is their wish, die at home with adequate care (AIHW, 2025b).

System performance and access in Victoria

Victoria shows strengths in timely access and anticipatory symptom management, but overall performance against DHDA's Australian Palliative Care Outcomes Collaboration (PCOC) benchmarks is average: 13 of 21 targets met, with persistent gaps in responsive symptom management, community-care timeliness, and equitable access (PCOC UOW, 2025). Inpatient and hospice services are generally more consistent, supported by specialist teams and 24-hour infrastructure, while community settings (non-admitted palliative care

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[1] Data only available at the National level.

[2] In some instances, individuals who go through the VAD process do not die from administration of a VAD substance. Applicants may choose not to proceed or may become too unwell and/or lose decision-making capacity and be unable to proceed.

services), where most people prefer to receive care, face workforce shortages, limited after-hours capacity, and fragmented coordination.

Access is often crisis-driven, reflecting structural issues in how services are understood, organised and funded. Late or unplanned referrals reduce opportunities for ACP and shared decision-making, as well as lower quality of life, and contribute to potentially preventable hospitalisations (AIHW, 2025b; DoH, 2016; Productivity Commission, 2017).

The structural factors that contribute to gaps in community timeliness also drives cost. In a national report, KPMG found that shifting earlier to community-led palliative care delivers better outcomes at lower cost, with savings of $1.68-$4.14 per $1 for nurse-led models in residential aged care and $1.36-$2.13 per $1 for hospital consult/liaison, alongside per-person savings from home-based care and advance care planning[3] (KPMG, 2020).

Inequitable access to palliative care

Access to timely, quality palliative care is influenced by the social determinants of health, including socioeconomic advantage, cultural or ethnic background, place of residence and diagnosis. These factors shape who receives palliative care, where, and when. Population groups most affected include:

- Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse communities, LGBTIQ+ communities, and people experiencing socioeconomic disadvantage or homelessness (Australian Healthcare Associates, 2019).
- Rural and outer urban communities, which often have fewer local services and limited after-hours options (AIHW, 2025b; Australian Healthcare Associates, 2019).
- People with non-malignant conditions (for example, COPD), as well as those living with dementia or disability. For example, dementia accounts for a higher proportion of deaths than of specialist palliative care recipients, and approximately one in 6 Australians live with disability, facing additional barriers to care (ABS, 2022; AIHW, 2025b; PCA, 2018)

These inequities often drive late or crisis referrals, reducing opportunities for early support, comfort and choice. These same social determinants also contribute to significant gaps in the data available to inform planning and service delivery. Persistent challenges in capturing cultural, linguistic, and diversity data mean that the needs and experiences of priority groups are often underrepresented or invisible in datasets. This limits the ability of health systems to identify and address inequities in palliative care, making improvements in data quality, completeness, and integration essential for supporting more equitable, person-centred care.

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[3] Based on a national economic report on palliative care. Local return on investment will vary by service mix and cost base.

2. Overview

2. Overview of palliative care in the NWMPHN region

2.1 Population and socio-demographics

Understanding population size, growth, and composition provides important context for assessing demand for palliative and end-of-life care services.

The NWMPHN region is one of the fastest growing and most diverse in Victoria, and the characteristics of its population shape both the volume and type of care required.

Figure 5. Key socio-demographic data about the NWMPHN region population

Population is projected to increase by more than 12 per cent by 2030, reaching nearly 2.3 million.

By that time, approximately one in three Victorians will reside in the region, contributing to a growing demand for primary care and community-based health services, including palliative care (PHIDU, 2025)[4].

Our region's population is generally younger than Victoria overall[5]. However, the fastest growth is expected among adults aged between 70 and 84.

With increasing age comes a higher prevalence of chronic and complex conditions, including cancer, dementia, and multimorbidity – conditions most likely to require palliative and end-of-life care (PHIDU, 2025).

There is substantial socioeconomic diversity, with areas of both high advantage and significant disadvantage.

Overall, our region has a higher level of disadvantage than Victoria as a whole, as measured by IRSD. Socioeconomic disadvantage is associated with poorer health outcomes, lower health literacy, and reduced access to early or appropriate palliative care (AIHW, 2025b; PCA, 2018; PHIDU, 2025).

Our region is home to one of the most ethnically and culturally diverse populations in Australia, with projected growth largely driven by immigration.

NWMPHN's region is more socially and culturally diverse than Victoria's overall profile. This necessitates holistic, culturally responsive palliative care tailored to different beliefs, communication needs, and family structures to ensure equitable and meaningful end-of-life experiences.

Figure 6. Key data about social and cultural diversity in the NWMPHN region population

A large proportion of our community identifies as of lesbian, gay, bisexual, transexual, intersex or queer/questioning.

The proportion people who identify as of lesbian, gay, bisexual, transexual, intersex or queer/questioning[6] (LGBTIQ+) is 6.7 per cent in NWMPHN region, compared to 5.7 per cent in Victoria as a whole (DoH, 2017).

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[4] Population growth is calculated using the 2024 ERP and 2030 projected population estimates.

[5] This is determined by comparing the proportion of the population in each 5-year age group in the 2024 ERP between NWMPHN and Victoria.

[6] LGBTIQ+ data is for Victoria and for people aged 18 years and older, calculated using data from 'The health and wellbeing of the lesbian, gay, bisexual, transgender, intersex and queer population in Victoria: Findings from the Victorian Population Health Survey' (2017). It is important to note that this data is likely an underestimate of the true LGBTIQ+ population in the region.

There are more than 230 languages spoken in our region, with many people born in non-English speaking countries.

Around 46 per cent of people living in the region speak a language other than English at home, compared to 33 per cent across Victoria. More than 33 per cent were born in predominantly non-English speaking countries – considerably higher than Victoria overall, which has 24 per cent (ABS, 2021; PHIDU, 2025).

Our population has diverse ancestry and religious practices.

More than one-third of the people living in region do not identify as religious. “Catholicism” and “Islam” are recorded in census data as the most common religions, at 23.5 and 8 per cent respectively. (We acknowledge that this classification does not properly capture denominational diversity.)

Excluding British and Australian ancestry, most people residing in the region have Southern Asian (12.4%), Southern European (11.3%) and Irish (7.5%) ancestry (ABS, 2021).

Detailed analyses of the NWMPHN population structure and socio-demographic profile are available in our 2025-28 region-wide HNA[6].

2.2 Population health and chronic disease prevalence

Chronic conditions are more prevalent among older adults, the fastest growing age group in our region. These conditions increase with age and contribute to potentially preventable hospitalisations that could be effectively managed in primary care.

Chronic conditions are non-communicable, progressive diseases, and represent the leading causes of ill health, hospital use and death. They underpin much of the demand for palliative and end-of-life care. Importantly, a substantial portion of this burden is preventable. Action on modifiable factors such as smoking, alcohol consumption, poor diet, physical inactivity, and obesity can reduce incidence and progression.

- 24 per cent of people in the NWMPHN region live with at least one chronic condition and prevalence increases with age (see **Figure 7**). Over half of all potentially preventable hospitalisations relate to chronic conditions that can be managed in primary care through multidisciplinary care (Falster & Jorm, 2017).
- There are generally more females than males living with chronic conditions, though the sex differences are small. Multimorbidity (that is, a combination of two or more chronic conditions) occurs at higher rates in older adults, particularly those aged at least 70. Rates increase with lower socioeconomic advantage and distance from urban areas.
- Sex differences are more pronounced among Aboriginal and Torres Strait Islander people, with females generally experiencing a higher prevalence and greater number of chronic conditions than males, except for heart diseases. Almost one in four First Nations females in the NWMPHN region live with at least one chronic condition and 12 per cent report two or more[7].
- There is limited data to understand chronic conditions among diverse cultural and ethnic groups or LGBTIQ+ communities in the region. Some of these data limitations are discussed later in this report, at section 4.3 Research question 3: Data and equity.
- Since 2013, cancer, circulatory, and respiratory diseases have been the leading causes of mortality in the NWMPHN region and Victoria (AIHW, 2025a). As shown in **Figure 8,** these life-limiting chronic conditions increase with age. Children under 10 and adults under 40 experience chronic conditions that are usually not life-limiting, such as asthma and mental ill health (Hvidberg et al., 2016). Research shows that cancer is a main cause of death among children who receive palliative care, followed by neurological and genetic conditions (AIHW, 2024b).

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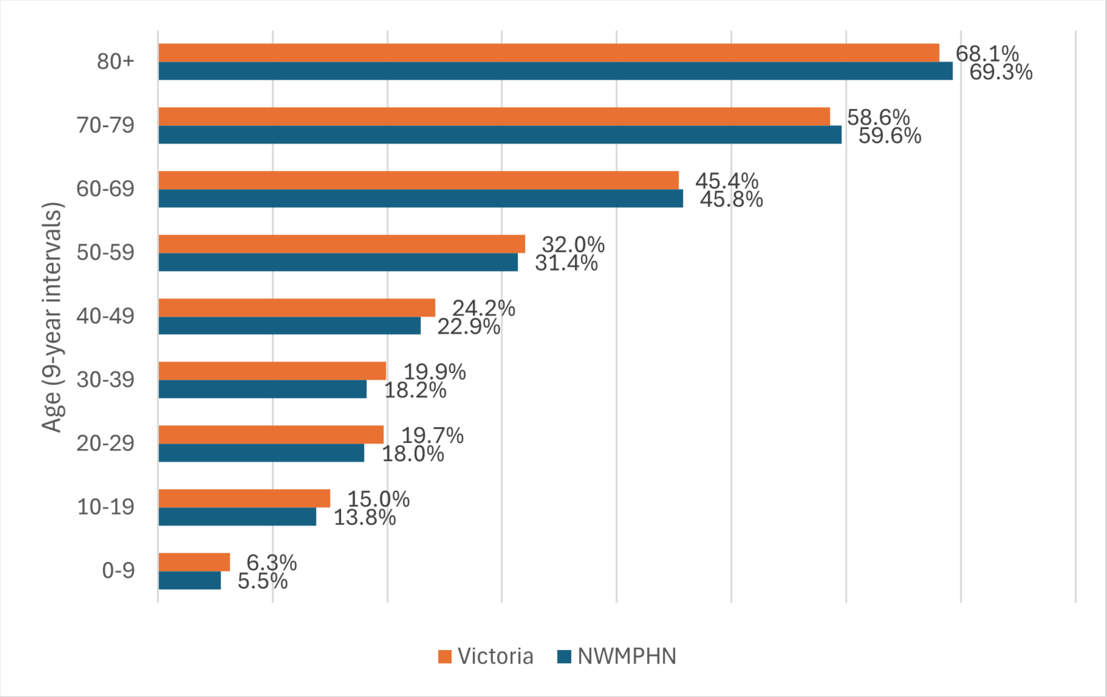
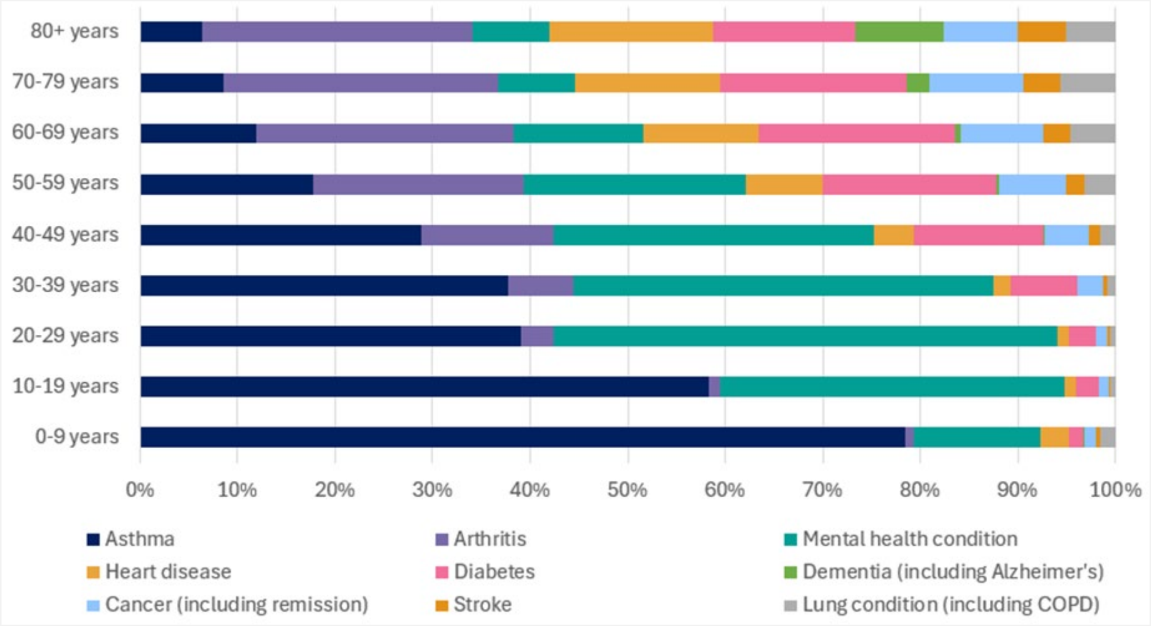
[7] Analyses of data to interpret findings for Aboriginal and Torres Strait Islander people reference and draw comparisons with the rest of the Aboriginal and Torres Strait Islander population, not the non-Indigenous population.

Figure 7. Proportion (%) of population living with at least one chronic health condition, NWMPHN region and Victoria, 2021 Census.



Source: ABS (2021)

Figure 8. Proportion of the population living with chronic condition by diagnosis group and 9-year age group intervals, NWMPHN region, 2021 Census.



Source: ABS (2021)

Detailed analyses of health conditions and consequences among the NWMPHN region population are available in our 2025-28 HNA[8].

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[8] See **Metric 5** (pp.101-137).

2.3 Access to palliative care services

Most palliative care is delivered by specialists – palliative medicine physicians and palliative care nurses – in hospital settings. However, most care can be provided by palliative care generalists (GPs, nurses, AHPs) and community-based specialist palliative care services (AIHW, 2025b; PCA, 2018).

This section investigates the four areas outlined in **Table 1** below to understand factors that influence effective palliative care delivery.

Table 1. Understanding factors that impact access to palliative care services in the NWMPHN region.

Area	What this tells us	Key questions we examine
Availability Palliative care workforce and health infrastructure	Supply and service readiness across community, primary care and hospital settings.	• Do we have enough generalist and specialist palliative care capacity in our region? • Where are the biggest workforce shortages, by health setting and profession?
Accessibility Reach and affordability	Whether people can access affordable care and support close to where they live.	• Who faces distance, after-hours or cost barriers? • What is the cost of palliative care in hospital and primary care settings?
Awareness Knowledge about palliative care and the death system and the ability to put that knowledge into practice	Whether people have the knowledge and skills that make it possible to understand and act upon end-of-life and death care options.	• How do levels of death literacy (such as knowledge and skills to understand and act upon end-of-life and death care options) among GPs and nurses in NWMPHN differ compared to national benchmarks?
Utility Use and intensity of palliative care services, including medication	Who is using palliative care and medicines and how much.	• How many people receive specialist and hospital-based palliative care services in our region? • What are the most common medications prescribed for people with a life-limiting illness? • How does service and medication utility compare to Victoria, and what factors drive increased use?

Table note: Adapted from the principles of Tanahashi's (1978) model of evaluation of health service coverage.

Important data limitations

There are several important data gaps and limitations that must be considered when interpreting information about palliative care services. These are:

- **No nationally consistent dataset captures generalist or community-based palliative care activity**. The MBS only includes palliative care items for palliative medicine physicians and specialists, and most public and community-based specialist palliative care is not recorded in MBS data. There are no equivalent palliative care-specific items for palliative care nurses or health providers who provide generalist palliative care, including GPs and other specialists such as oncologists, primary care nurses or AHPs.
- **Information is not readily available on the number of people living with a life-limiting illness who might benefit from palliative care, but aren't receiving it**. Nor is information available about people who provide care to a person with a life-limiting illness. Without this information it is challenging to accurately assess the potential demand and anticipated utility of palliative care services within the region should these people be referred early into services as indicated by best practice.
- **National registration information unavailable on other AHP disciplines, such as social work or pastoral care, that are routinely involved in aspects of palliative care**.

Availability of palliative care

Palliative care is delivered in many settings, including homes, hospitals, hospices, residential aged care, general practices, specialist clinics, and community-based services. Across all areas where it is provided, the need for palliative care is increasing but has not been accompanied by necessary additional investment in services or the workforce (PCA, 2025).

Figure 9 demonstrates the various settings in which palliative care may be delivered through community-based and hospital-based support. Across these, care is delivered by a varied and multidisciplinary workforce. The workforce can be divided into two broad categories **(PCA, 2025)**:

- **Specialists**, including health professionals with advanced specialised training and experience, as well as specialist palliative care social workers, spiritual care practitioners, trained palliative care volunteers and art and music therapists.
- **Generalists**, including health professionals and other practitioners or community members involved in palliative care who may not have specialised training and experience. These include pharmacists, paramedics, physiotherapists, occupational therapists, speech pathologists, dieticians and Aboriginal and Torres Strait Islander health workers and practitioners. Also recognised as part of the team are those providing care to people with life-limiting illness, such as carers (DHDA, 2025).

The accessible data needed to understand the availability of these workforces across our region is captured in **Table 2**.

Access to non-GP medical specialists is challenging across the NWMPHN region and patients may rely on their GP to provide more care. In some areas, access to a GP is also an issue. These challenges are pronounced in areas with social disadvantages and high population growth.

The data shows:

- The availability of FTE generalist palliative care workforce is mostly lower in NWMPHN (measured per 100,000 population) compared to state and national levels (**Table 2)**. Access to non-GP medical specialists is challenging across the NWMPHN region. There is a strong hospital nursing and pharmacist coverage but significant gaps in aged care nurses and Aboriginal and Torres Strait Islander health practitioners, which may impact culturally safe and community-based care.
- The availability of FTE specialist palliative care workforce is mostly lower in NWMPHN (measured per 100,000 population) compared to state and national levels (**Table 2**). While availability in the region meets

or exceeds benchmarks for palliative and pain medicine specialists, access to these specialists is often limited in community-based settings, which may increase demand on generalist providers. There is a shortfall in palliative care nurses, particularly in community and residential settings, limiting non-hospital palliative care capacity.

Figure 9. Palliative care settings

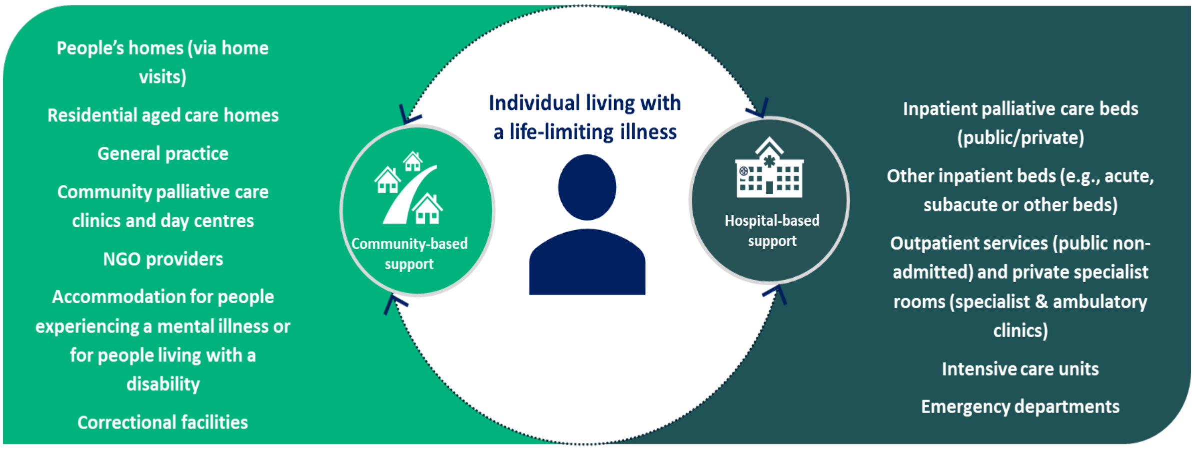


Figure note: Adapted from the *Palliative Care Service Development Guidelines* (PCA, 2018). Palliative care is provided across a range of community and hospital-based settings, with people living with a life-limiting condition often transitioning between settings throughout their illness trajectory. Palliative care and end-of-life care is provided by generalists (GPs, other medical specialists including oncologists and radiologists, nurses, AHPs and pastoral care) and palliative care specialists (palliative medicine physicians and palliative care nurses).

Table 2. Key data on the specialist and generalist palliative care workforce data in the NWMPHN region, Victoria and national level.

Role	Measure (FTE per 100,000 population)	NWMPHN	Victoria	National
Generalist	General practitioner[1]	**111.0**	115.6	111.4
	Primary and community nurses[1]	**231.9**	238.5	242.0
	Nurses in hospitals[1]	**939.0**	848.7	837.5
	Nurses in aged care[1]	**151.8**	238.4	202.3
	Pharmacists[2]	**120.9**	104.5	100.5
	Aboriginal and Torres Strait Islander health practitioners[2]	**0.3**	0.6	2.8
Specialist	Palliative medicine specialist[3]	**1.3**	1.0	1.3
	Pain medicine specialist[3]	**1.0**	1.0	0.9
	Palliative care nurse[3]	**10.9**	14.5	13.1
	Palliative care nurse in general practice[3]	**0.0**	0.0	0.0
	Palliative care nurses in hospital[3]	**7.2**	7.4	6.5
	Palliative care nurse in community health[3]	**2.7**	3.8	3.5
	Palliative care nurse in residential health care facility[3]	**0.0**	0.1	0.2
Carers	Carers[4]	**8497.8**	9875.9	9107.3

Table note: Red = below state and national. Yellow = below state. Carers = the total number of carers per 100,000 population not an FTE estimate and uses the ABS Census variable 'Unpaid assistance to a person with a disability, health condition or due to old age'. FTE per 100,000 population calculated using 2024 ERP (PHIDU 2025).

Source: [1]HeaDS UPP, FY2024-25; [2]NHWDS, CY2023; [3]NHWDS, DHAC, CY2024; [4]Keystone Data,

The role of carers in palliative care

Caring for someone who is dying is an individual commitment and can be a rich, rewarding and challenging experience. There is often a heavy emotional strain associated with caregiving at the end of life, with carers potentially experiencing fatigue, resentment, social isolation and stress.

The extent and quality of support provided to a carer and the person receiving palliative care is key to the experience they both have, according to Palliative Care Australia.

Providing palliative care at home can require family members and carers to assist with personal care tasks and symptom management, including administering medication. Palliative care providers can assist carers to feel confident attending to these tasks. Specialist palliative care services may also provide respite, grief and bereavement counselling, and other services to support carers and families.

Key data about carers includes:

3 million
carers in Australia 2022
(2.6 million in 2018)

750,00
(12%) of Victorians provide unpaid care to elderly and those with a disability

300,00
(40%) of these Victorians are primary carers

39%
of Victorian carers live with a disability

NWMPHN region

9.5%
of NWMPHN region's population are carers

28,000
(16.3%)
of carers are aged 65 years or older

60%
of carers are female

6,000
(3.5%)
of carers are aged 25 years or younger

Note: This data reflects those providing unpaid care to people due to disability, health condition or ageing. Data on those caring for someone receiving palliative care is not available (ABS, 2022).

Access to palliative care

Access to GPs, palliative care services and hospital-based supports vary across the NWMPHN region.

Accessibility coverage in health care determines whether individuals can access services regardless of location, financial status, or physical limitations. This includes geographic, financial or physical accessibility.

Key terms and definitions

These definitions are adapted from AIHW's palliative care service web report (2025b).

Bulk-billing: The process whereby a patient assigns their entitlement to a Medicare benefit to the treating practitioner, who in turns, submits the claim directly to Services Australia. The practitioner cannot charge a co-payment, so there are no out-of-pocket costs.

Medicare Benefits Schedule (MBS): The MBS lists the medical services subsidised by the Australian Government, including those provided by GPs, specialists, and allied health professionals. In this document, MBS palliative care services refer to consultations, case conferencing, and multidisciplinary planning items claimed under palliative care-related MBS codes.

MBS-subsidised palliative medicine attendance and case conference services: Services provided by palliative medicine physicians or specialists and are claimed under specialist palliative care MBS item numbers. (A full list of MBS palliative care items is available at within AIHW's palliative care service web report).

Geographic, health infrastructure and cost barriers

There is significant variation in the geographic distribution and cost of palliative care services in the NWMPHN region, which contributes to inequitable access to timely and high-quality care. This disparity is particularly challenging for individuals with lower socioeconomic status, those living with disabilities, and residents with culturally diverse backgrounds, who often face additional barriers to accessing appropriate palliative care services.

The availability of GPs, residential aged care homes, pharmacies, and community health services typically declines as the distance from Melbourne's city centre increases. This disadvantages people living in outer or peri-urban LGAs, who must travel further to access services such as bulk-billing GP clinics and specialist palliative care providers, increasing time and cost burdens for people with a life-limiting condition and their families (Davern et al., 2023).

Timely access to health services is compounded for people, including:

- Those with low individual or household incomes, because costs associated with public transport, accommodation, time away from work, out-of-pocket expenses for primary care, and private health cover can delay care.
- Those from culturally diverse populations, who may need to travel farther to find inclusive and tailored services, peer-led support, or culturally safe services in their language.
- Those who rely on a carer or family member for transport or financial support, or whose illness or disability makes travel difficult. For example, initial VAD consultation must be in-person under current legislation and cannot be offered via telehealth. Approximately two-thirds of registered and authorised VAD practitioners are metropolitan based. This can become more complex when the primary caregiver is also older or has a disability (DoH, 2025).

While private care can provide faster access and a greater choice of specialist palliative care physicians, fees and availability can limit equitable access, as shown in **Table 3**. Although most public services are free or aim to minimise out-of-pocket costs for palliative care, some marginalised groups face barriers related to Medicare ineligibility–including temporary visa holders, people experiencing homelessness, and those in unstable housing– leading to unequal access to MBS and PBS rebates.

Distance, service distribution and cost interact, leading to delayed access to the right care in the right place, increasing the risk of delayed or forgone care, avoidable emergency department use, and poorer health outcomes and quality of life. These factors shift preventable pressure and costs onto hospitals and emergency care (AIHW, 2025b).

Table 3. Palliative care services and support costs across different care settings.

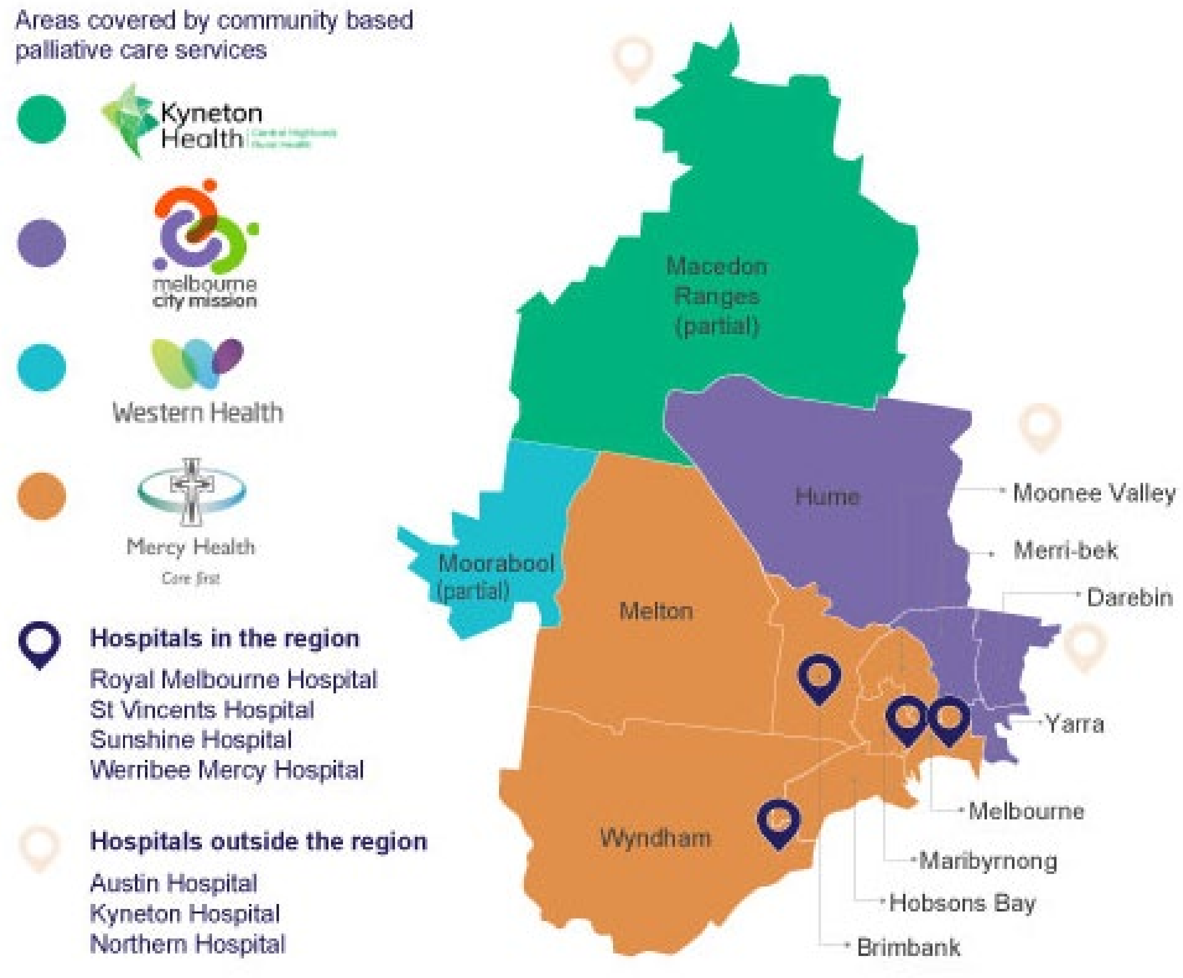
Community-based support		
Specialist community palliative care services *For example, Melbourne City Mission Palliative Care, Mercy Palliative Care, Kyneton Health Palliative Care*	Activity-based funding (ABF) (non-admitted)	**No cost for public patients**[1]
General practice *Local GP clinics, home visits, RACH, telehealth*	MBS (GP items only)	**Bulk billed (no out-of-pocket cost)** or **gap fee**
Private specialist palliative consults *Palliative medicine specialists' private rooms, telehealth*	MBS (specialist items)	**Gap fee**[2] *varies by provider*
VAD consultation *VAD consultation or assessment in usual clinician setting*	No VAD MBS item[3] *billed under GP/specialist item*	**Bulk billed (no out-of-pocket cost)** or **gap fee** *no separate VAD fees apply*
Palliative care-related medication *Community-based pharmacy*	PBS	**PBS gap fee** *lower for concession*
VAD medication dispensing Statewide pharmacy service	State-funded	**No cost**
Hospital-based support		
Public hospital (inpatient) palliative care admission. *Care provided by public hospital palliative care unit (specialists and generalist care)*	ABF (acute, sub-acute and non-acute)	**No cost for public patients**[1]
Public hospital (out-patient) *Examples include, hospital-run home-visits, RACH and telehealth by, for instance, Mercy Health SMART clinic, specialist palliative outpatient clinics, Northern Health Symptom Management Clinic*	ABF (non-admitted)	**No cost for public patients**[1]
Private specialist palliative consults *Palliative medicine specialists' private rooms, telehealth*	MBS (fee-for service)	**Gap fee** *varies by provider*

Table note: [1]*Out-of-pocket "gap" = provider fee − Medicare rebate.* [1]*$0 medical fees for public patients excludes incidentals such as transport/parking, accommodation, ambulance fees, and some discharge medicine.* [2]*Out-of-pocket "gap" = provider fee − Medicare rebate. Private health insurance generally does not cover out-of-hospital medical consults.* [3]*No dedicated MBS item for VAD. In Victoria, the VAD navigation service and statewide pharmacy are state funded; VAD medication is supplied at no cost. Clinician time is billed under usual consult items or covered by hospital salary.*

Geographic distribution of palliative care services in the NWMPHN region

The map below in **Figure 10** highlights where community-based and hospital-based palliative care is available within the NWMPHN region. See Appendix A for a full list of palliative care services and Appendix B for a full list of palliative care programs.

Figure 10. Map of community-based and hospital-based palliative care services in the NWMPHN region.



Utility of specialist palliative care services

Palliative specialist care services appear underutilised in our region, compared with Australia as a whole. This indicates barriers to access and availability. This section presents insights about the utility of specialist palliative care provided in hospital-based and community-based settings.

Key information for data interpretation

Palliative care is coded in different ways, which can impact the accuracy of inpatient data and may result in underreporting of specialist MBS items, even when palliative care is being provided.

- MBS 'palliative' items primarily capture private-sector specialist billing. Most public and community-based specialist palliative care is not recorded in MBS data.
- GPs and allied health professionals (AHPs) provide palliative care, but do not bill under specialist palliative codes. As a result, their palliative activity does not appear in MBS data.
- Public hospital inpatient and outpatient clinics, and community-based palliative care teams, are activity-based funded (ABF). Palliative care activity in these settings appears in hospital datasets, rather than in MBS data.

The matrix and scenarios below provide guidance on how to interpret the findings in this section.

Admission category	**Principal diagnosis** Palliative Z51.5 ICD-10-AM	**Additional diagnosis** Palliative Z51.5 ICD-10-AM	**Care type** Palliative
Primary palliative care *The main reason for admission is a principal palliative care diagnosis.*	✓	✗	✓ or ✗
Palliative care-related (secondary) *Admitted for another condition with a secondary palliative care diagnosis. The care type is not palliative*	✗	✓	✗
Other palliative care *Admitted for another condition and may or may not have palliative care as an additional diagnosis.*	✗	✓ or ✗	✓

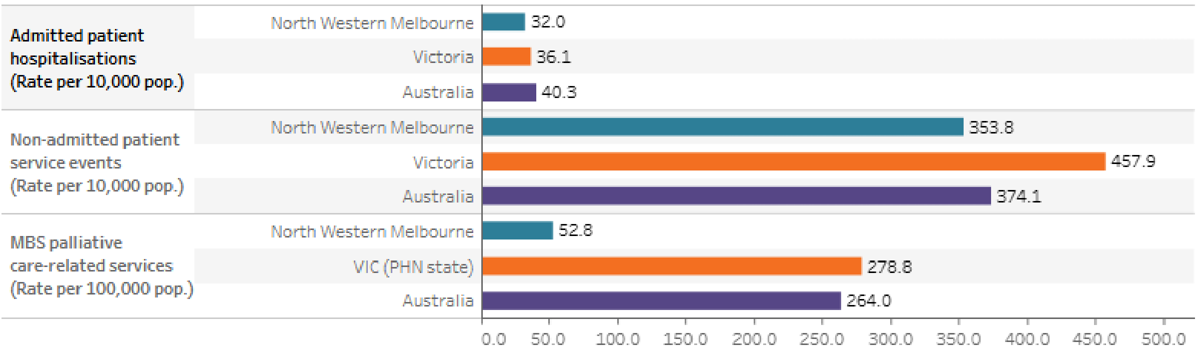
Category	**Scenario**	**Principal diagnosis**	**Additional diagnosis**	**Care type**
Primary palliative care	*A 72-year-old with metastatic pancreatic cancer is admitted primarily for palliative care rather than disease-directed treatment and receives pain and nausea management and a family meeting to establish goals of care.*	Palliative care	Cancer	Palliative or acute
Palliative care-related (secondary)	*A 90-year-old from an RACH is admitted with an acute COPD flare. The medical team keep the episode as acute care. The palliative team provides symptom relief and care planning during the stay.*	COPD	Palliative care	Acute
Other palliative care	*An 84-year-old with end-stage heart failure is admitted to the palliative care unit for breathlessness and medication adjustment. The team sets the care type to palliative, but the main diagnosis remains heart failure.*	Heart failure	N/A	Palliative

Episode of care: the counts included in the analysis for rates and numbers use episodes of care. This is not the same as 'a patient', because multiple episodes of care can be recorded per individual. This can appear to inflate numbers in a region where there are multiple re-admissions.

Despite being one of Australia’s largest populations, substantially fewer people with a life-limiting illness receive specialist palliative care per capita in the NWMPHN region, and those who do receive fewer services per person than in most other PHN regions. Data from AIHW’s PHN palliative care services information (2025b) shows that:

- **Specialist palliative care use in the NWMPHN region is below state and national benchmarks.** The greatest difference occurs in outpatient/community-based care, where utility rates are 34 per cent lower than Victoria (see **Table 4**). For hospital admissions, utility rates are 13 per cent higher in Victoria and 26 per cent higher nationally. Low utility may reflect limited local capacity in community specialist services (such as fewer clinics, outreach or home-visits).
- **Service use also varies widely across Victoria**. South Eastern Melbourne PHN (SEMPHN) and Western Victoria PHN record rates 6-12 times higher than NWMPHN. Our region’s outpatient and community-based service intensity is also lower. On average, people receiving palliative care have only 3.2 visits per person, compared with Eastern Melbourne PHN (5.4) and SEMPHN (7.3).
- **Despite low relative utility and intensity, NWMPHN has one of the highest numbers of palliative care-related hospital admissions due to its large population size.** As shown in **Figure 13**, there were more than 6,020 hospitalisations in NWMPHN in 2022-23 – accounting for nearly 7 per cent of the 100,420 recorded nationally.

Figure 11. Summary of admitted patient hospitalisations, non-admitted patient service events and MBS palliative care-related services in NWMPHN, Victoria and Australia.



Source: AIHW, PHN palliative care services information, (2025)

MBS-subsidised specialist palliative care (physician attendances and case conferences)

Consistent with the hospital findings, 2022–23 MBS data[9] show substantially lower local specialist activity than in Victoria and Australia.

- Only 1.6 people per 10,000 received MBS-subsidised palliative care services (from a palliative medicine physician), in contrast to Victoria and Australia rates, which were approximately three times higher (**Table 1**).
- The volume of MBS specialist palliative services delivered in the NWMPHN region is approximately 80 per cent lower than in Victoria as a whole and the national rate (see **Table 4**).

Service intensity is lower because fewer people are seen by palliative specialists, and fewer services are billed locally.

- Approximately 300 people received 970 services (averaging 3.2 per person), below that recorded in other metro PHN regions (AIHW, 2025b).
- MBS activity is concentrated in consulting-room/hospital settings (275 people; 811 services in 2022–23), with community/out-of-hospital claims rare or not published. Consistent with this, hospital data presented by primary health network regions show higher palliative care rates recorded in public than private hospitals, though private activity is likely under-counted due to coding differences (AIHW, 2025b).

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[9] Note: MBS figures are for **2022–23** which is the latest available on from AIHW’s PHN palliative care services information (2025b)).

Table 44. Comparative rates of specialist palliative care service utility for the NWMPHN region, Victoria and Australia (2023-24). Percentage differences are compared to NWMPHN.

Region	**Hospital and community-based specialist utility**		**MBS specialist palliative care utility**	
	Hospital admission rates Episodes per 10,000 population in 2023-24[11]	**Non-admitted patient palliative care service events** Events per 10,000 population in 2023-24	**People receiving MBS -subsidised specialist palliative services[10]** Per 10,000 population in 2022-23	**MBS-subsidised specialist palliative services delivered** Per 10,000 population in 2022-23
NWMPHN	**32.0** (6,323)	**353.8** (69,814)	**1.6** (302)	**5.1** (970)
Victoria	**36.1** *+12.8%*	**457.9** *+29.4%*	**4.4** (2,941) *+175%*	**26.0** (17,376) *+405%*
Australia	**40.3** *+25.9%*	**374.1** *+5.7%*	**5.4** (13,921) *+234%*	**26.4** (66,334) *+415%*

Table notes: Hospital rates (admitted and non-admitted) use AIHW NHMD and NNAP(el)D 2023–24. MBS figures use AIHW PHN Tool 2022–23 due to different data release cycles.

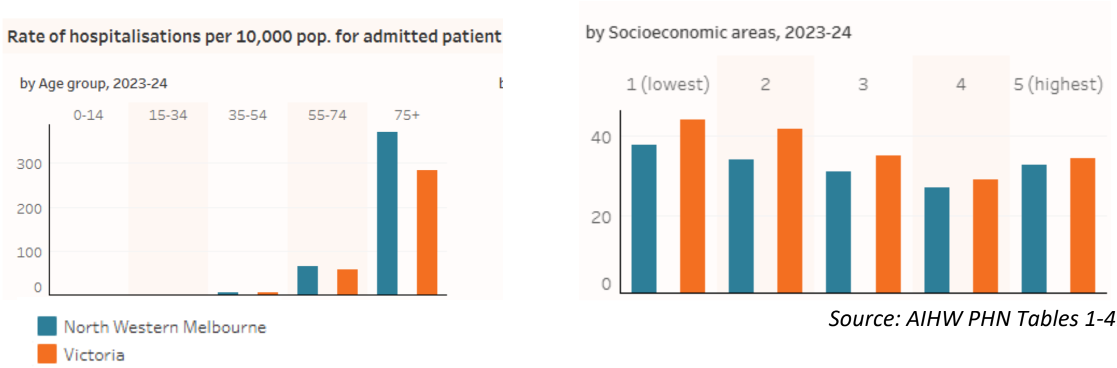
Source: AIHW NHMD and NNAP(el)D, 2023-24,

Socio-demographic factors

Rates are generally higher in more disadvantaged areas (IRSD 1–2), but the gradient is modest, indicating broad need across the region, not only in the most disadvantaged communities.

- Admissions rise steeply with age (**Figure 12a**). People 75+ account for twice the number of admissions compared to those aged 55–74, and comprise an admission rate approximately six times higher, supporting evidence for a much greater need for palliative care in later life. The rate of hospital admissions for adults aged 55+ was higher than the Victorian average and increases past 75. Younger groups, especially under 35, contribute very little by rate or count.
- After adjusting for population age, use of specialist care has remained stable over the decade 2013-23 while increased crude utility rates reflect an ageing, growing population *(AIHW, PHN palliative care services information 2023-24).*

Figure 12 Rate of hospitalisations per 10,000 population for admitted patient palliative care by (a) age-group and (b) socioeconomic status (IRSD 1-5) (2023-24).



Source: AIHW PHN Tables 1-4.

By principal diagnosis: cancer or non-cancer conditions

Non-cancer conditions drive almost two-thirds (65 per cent) of palliative care hospitalisations (8,138 of 12,646) across all admission types (AIHW, 2025)

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[10] People can receive more than one MBS subsidised service, which tells us about service intensity.

- Admissions where palliative care is recorded as a secondary diagnosis are more common than primary palliative care admissions for cancer and non-cancer groups. This aligns with coding/clinical practice[12] where palliative care frequently supports hospitalisations coded to an underlying condition (for example, heart failure, COPD, dementia).
- Within the 'non-cancer' hospitalisations, approximately half are palliative care-related, one-third other palliative care admissions, and the remainder primary palliative-care admissions (**Figure 13**). This supports the pattern above, where most activity is palliative input to episodes coded to an underlying disease.

Figure 13. Rate of hospital admissions per 10,000 population for admitted patient palliative care by principal diagnosis, (2023-24).

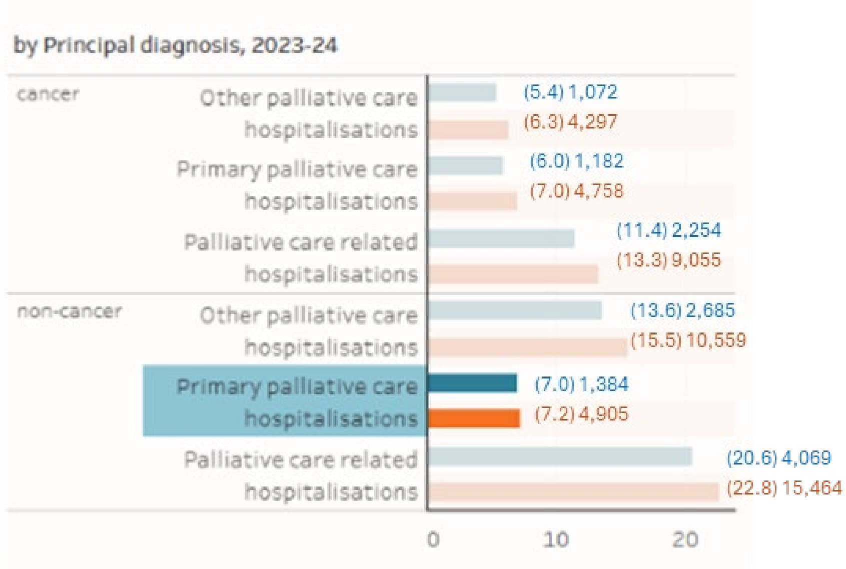

Figure note: Primary palliative-care diagnoses are likely under-counted because coding often prioritises the acute/underlying condition as the principal diagnosis. This suppresses primary palliative-care counts and inflates palliative-care-related (secondary) counts.

Source: AIWH, PHN tables 1-4 (2023-24).

What does this tell us? That there is a strong case for shared models of palliative care.

- Differences in models of care partially explain variations in admission rates. Cancer care pathways often provide clearer outpatient and community support, including shared-care arrangements, so more people's needs are met by primary care providers outside the hospital, reducing primary palliative care admissions. This supports the tiered model of palliative care in which generalists manage straightforward, predictable needs in the community, while specialist roles increase as complexity and persistence increase across settings.
- In contrast, chronic condition pathways are generally more variable and involve multiple health conditions, resulting in more frequent admissions that require palliative care. These inpatient cases are typically coded to the primary condition, with palliative care recorded secondarily. For more information, refer to the themes in the Australian Government's Australian Cancer Plan and Palliative Care Service Development Guidelines, which emphasise the importance of coordinated, evidence-based supportive and palliative care across different healthcare settings.

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[12] See AIHW definitions of 'primary palliative care', 'palliative-care-related', and "other palliative care" hospitalisations.

Palliative care-related medication usage

Pain relief medicines are the main palliative care prescription type in the NWMPHN region, yet overall utilisation remains below the Victorian and national rates.

Key terms and definitions

Pharmaceutical Benefits Scheme (PBS) is a government subsidy that reduces the cost of some prescription medications. The subsidy improves affordability and accessibility to essential and clinically effective medicines and is accessible to Australian residents and eligible visitors who have a Medicare card. In this report, PBS palliative care medicines refer to medications listed under the **PBS Palliative Care Schedule,** which supports symptom management and quality of life for people with life-limiting illnesses.

Unlike MBS palliative care items, which can only be used by specialists, PBS items can be prescribed by specialists and generalists. As a result, dispensing rates for palliative-related medicines are 16 per cent lower than state and national benchmarks.

Specialist MBS activity appears 80 per cent lower (**Figure 14**) because generalist palliative care services are billed under general MBS items and therefore obscured.

Further compounding visibility of palliative care use, the PBS does not capture prescriber specialty. This means specialist and generalist prescriber cannot be distinguished, limiting ability to identify the scale of GPs providing palliative care support. A lack of individual patient identifiers means repeat prescriptions and dose changes can inflate total counts.

- An estimated 31,000 people in the NWMPHN region received PBS palliative care-related medicines in 2022-23, accounting for approximately seven per cent of all users nationally.
- This is a lower rate of people receiving PBS medication (164.8 per 10,000 people) than those found in Victoria (184.1) and Australia (174.6) *(AIHW table 7).*
- Prescriptions per person were slightly lower than the national average of 3.0.

Medication usage

- Pain relief medication was used by 80 per cent of people receiving palliative care. Non-opioid analgesics and antipyretics were the most prescribed (comprising over 40 per cent of pain relief prescriptions), followed by opioids (30 per cent) and anti-inflammatory/antirheumatic agents (27 per cent).
- Other palliative care medication groups besides pain relief (such as neurological or psychological) are used less often but still contribute a meaningful share of prescribing. (see **Figure 14**).
- Medication is strongly age-related. Adults aged 75+ represent 35 per cent of all users. They have the highest rate (9,949 per 100,000) and most prescriptions per person (3.0) (see **Figure 14**). These findings are consistent with higher prevalence of chronic and end-of-life conditions in older adults (section 2.1, 2.2 of this report).
- The 55–74 age group also contributes significantly, with 35 per cent of prescriptions, showing that palliative care needs extend beyond the oldest cohort.
- The overall mix and age pattern in the NWMPHN region is broadly consistent with Victoria and Australia, where pain relief medicines make up the majority of palliative care prescribing. Understanding prescriber type (GP vs specialist) and care setting would help explain local variation and service accessibility.

Figure 14. Rates of prescriptions per 100,000 population for PBS palliative care related medications, 2023-24.

Source and notes: AIHW. PHN Tables 7-8.
https://www.aihw.gov.au

Source: AIHW PHN Dashboard: PBS palliative-care-related medicines, 2022–23/2023–24

Awareness of palliative care services

Awareness is essential for ensuring access to palliative and end-of-life care. Health professionals and community members require knowledge of services available to support patients, families, and carers throughout their illness trajectory.

Knowledge about death and end-of-life issues helps individuals prepare, make informed decisions, and better understand the dying process. This understanding can reduce fear, promote acceptance, and improve the quality of care and support provided. Importantly, increased awareness of the scope of palliative care services can enable timely referrals to appropriate services, enhancing access and equity.

- Noonan et al. (2024) state that "Death literacy is knowledge and skills that make it possible to gain access to, understand and act upon end-of-life and death care options". It is a key dimension of awareness in the palliative context, which includes practical, experiential, and community knowledge to navigate end-of-life care effectively. This is crucial because higher death literacy empowers practitioners and communities to plan well, support families, and make informed choices, ultimately improving equity and quality of care.
- A resounding message from consultations with members of NWMPHN's Older Adults Expert Advisory Group, and its Clinical and Community Councils, was that more work is required to improve awareness of palliative care and to address the common misconception that it only applies in the terminal phase of illness. In these sessions, members noted the role of stigma and confusion around palliative care, especially with families, but also among health professionals, in identifying when individuals are ready for it. They also suggested that palliative care currently faces an image problem. More education is essential to improve the often-stigmatising ways we talk about it, and to build understanding of how to navigate our complex end-of-life and death systems.
- Given the importance of death literacy in palliative care awareness, NWMPHN set out to understand its levels across the NWMPHN region. To establish a baseline, the nine-question version of the Death Literacy Index (DLI-9) was distributed. A total of 32 responses were received, including 14 from GPs, 13 from nurses (10 of whom were practice nurses), three from practice managers, one from a health

promotion program manager and one from a mental health peer worker. The survey results are summarised in **Figure 15**.

- The survey results are summarised in **Figure 15**. The response rate was not sufficient for a representative sample of the NWMPHN region; thus, insights are limited and likely to reflect the characteristics of the 32 respondents. Nonetheless, this is the first time that death literacy levels have been measured here. While the findings have limited generalisability, they provide valuable insights, and when triangulated with other data, add further depth of understanding (see **Section 4. Findings**).

Figure 15. Key insights from a Death Literacy Index survey in NWMPHN

Respondents reported higher overall death literacy than national benchmarks for health/medical practitioners (7.14 vs. 6.51). Practical and experiential knowledge was rated highest, reflecting confidence in discussing death, providing hands-on care and applying skills from direct end-of-life experiences.

Factual and community knowledge scored lower, indicating gaps in understanding the death system and awareness of community services and supports. This may suggest that practitioners have knowledge gaps in terms of services or how to connect patients and families to them. If practitioners lack understanding of the death system (legal, financial, and care planning processes), patients may miss opportunities for advance care planning, leading to fragmented or delayed support.

Compared to other roles, practice nurses showed the largest gap between their knowledge domains with practical/experiential knowledge rated considerably higher (7.3) than factual/community knowledge (4.90). Given that practice nurses are vital for patient engagement, this knowledge gap could limit their ability to guide families toward community resources, impacting continuity of care.

3. Methodology

3. Methodology

3.1 Research method

A needs assessment implies a gap or discrepancy between the current conditions – 'what is' – and the ideal conditions – 'what should be'. This gap – the difference between the current condition and the ideal condition – is the 'need' (Smart, 2019).

The PCNA's evidence-based approach to understanding needs in the palliative care context was developed to meet its objectives and included three steps:

Step 1: Evidence base development

This involved building an evidence base on palliative care at national, state, and NWMPHN region levels. It included examining palliative care as a public health priority, reviewing key frameworks, relevant policy and legislation, and identifying current system factors and challenges.

Activities undertaken during this stage included:

- **Rapid review of grey literature:** Key challenges and recommendations from selected grey literature were synthesised across the five priority areas for the PCNA outlined by DHDA[13]:
    1. Workforce capacity and distribution.
    2. Service availability and access.
    3. Cultural, linguistic and other diversity considerations.
    4. Coordination between primary, community and specialist care.
    5. Community awareness and understanding.
- **Development of targeted research questions:** Research questions were formulated based on the challenges identified in the rapid review. To ensure alignment with NWMPHN's remit and service-planning needs, members of the NWMPHN GCfAHPC program team prioritised and selected the final questions.
- **Analysis of population data:** Due to limited availability of PHN-level palliative care data, existing analyses were utilised, including NWMPHN's 2025-28 Health Needs Assessment and AIHW's *Palliative Care Services in Australia* report.

Step 2: Targeted evidence gathering and analysis

Building on the evidence base from Step 1, the second step focused on in-depth data collection and analysis aligned with each research question.

Key activities undertaken during this stage included:

- **Targeted literature reviews.** Three targeted literature reviews were completed, concentrating on high-quality systematic reviews with a priority on the Australian context. The scope was constrained by project limitations, such as being able to use only open-access publications. Each review employed research-question-specific search terms across databases such as the CareSearch Systematic Review Collection, PubMed, Embase, Medline, and Web of Science.
- **Primary care provider consultations.** Six in-depth semi-structured interviews were undertaken, involving in total 14 primary care professionals who provide palliative care in the NWMPHN region. These consultations followed a structured protocol designed to explore regional challenges in delivering palliative care and to assess the practicality of solutions identified in literature. Analysis included the following:

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1. Inductive qualitative analysis was performed whereby transcripts from interviews were analysed and key words and phrases were coded. Codes were used to derive at set of sub-themes which were then grouped into high-order themes. This resulted in a qualitative framework (see **Appendix F**). Quotes were extracted according to their original code to further enrich insights developed through thematic coding.
2. To assess the effectiveness and feasibility of strategies, participants ranked "how effective do you think each strategy would be in improving palliative care/ACP in your context?" on a scale from most effective (1) to least effective (10). They were also asked to rank "How feasible (e.g., time, staff, resources, financial costs) is each strategy in your setting?" on a scale from 1-5, where 1= not at all feasible, 5= highly feasible. To get overall scores, for each strategy, the average of the sum ranking scores was taken. These quantitative scores were used in a mixed-method analysis with qualitative insights to provide insights.

- **Death Literacy Index survey**: The Death Literacy Index (DLI) is used to measure knowledge and skills among primary health care professionals related to supporting informed end-of-life choices, as well as factors influencing death literacy. The short version (DLI-9) comprises nine items on Practical Knowledge, Experiential Knowledge, Factual Knowledge and Community Knowledge scales. The DLI-9 was disseminated through nine channels (see **Table 6** for detail), including paid social media campaigns, NWMPHN newsletters, and primary care mailing lists. A total of 32 completed surveys were received. This was scored as per the DLI-9 ((Noonan et al., 2024).

- **Internal NWMPHN staff consultation:** Two in-depth semi-structured interviews were conducted with five NWMPHN staff members from two teams supporting primary health care improvement and data capability. A structured protocol guided these discussions to:
    1. Assess strengths and limitations of the demographic data on diverse populations.
    2. Identify opportunities within the PHN remit to enhance primary care data collection via Outcome Health's POLAR (Population Level Analysis and Reporting) tool, which NWMPHN utilises for data extraction from general practices.
    3. Evaluate the potential benefits of accessing PalCare data.

- **Assessment of work prior:** Insights in reports and resources resulting from prior work completed within the GCfAHPC program were assessed. These included:
    1. *Dying Well Community Panel* (2018), a GCfAHPC pilot activity which aimed to improve strategies for caring for people who are dying. The panel comprised 27 people from various backgrounds exploring the topic: "What does dying well look like and how can we help people achieve this?"
    2. Primary care provider survey (2022), focused on better understanding how community palliative care works with GPs.
    3. Internal review of GCfAHPC program activities and recommendations (2025).
    4. Outcomes from the *Palliative Care Spotlight,* a facilitated quality improvement project developed by NWMPHN, which aimed to improve GP capacity in providing palliative care and assisting with ACP.
    5. Peer consultations with other PHNs, exploring the potential for piloting shared care model projects.
    6. Consultations with the 35 members of NWMPHN's Clinical and Community Councils and Older Adults Expert Advisory Group (2025) which explored gaps in palliative care work following re-funding of the GCfAHPC program.

A detailed table regarding groups consulted is available in Appendix D and the protocols used in Appendix F. The qualitative framework that resulted from external consultations is available in Appendix E.

Step 3: Triangulation of evidence

Qualitative and quantitative data from Steps 1 and 2 were synthesised to generate comprehensive insights for each research questions. This triangulation process integrated findings from multiple data sources to strengthen validity and enhance the depth of analysis.

Table 5 outlines the triangulation approach used in Step 3 to address each research question. This process ensured findings were corroborated across sources, resulting in a robust evidence base to inform subsequent recommendations.

Table 5. Evidence base used for triangulation on each research question

RQ #	Focus	Evidence base for triangulation
RQ 1.	**Communication and awareness**	• **Literature review:** Synthesised thematic insights on the role of communication role in palliative care and the needs of patients, families, and carers. • **External consultations:** Compared local insights with literature findings to identify alignment and expand understanding of practical challenges. • **Death literacy survey:** Incorporated survey results to contextualise how death literacy influences communication effectiveness. • **Prior work**
RQ 2.	**Knowledge and capability**	• **Literature review:** Identified behavioural drivers and barriers using COM-B and TDF frameworks. • **External consultations:** Validated findings and assessed feasibility of evidence-based strategies. • **Death literacy survey:** Provided additional context on communication-related challenges. • **Prior work**
RQ 3.	**Data and equity**	• **Literature review:** Highlighted systemic data challenges. • **Internal consultations:** Explored strengths and limitations of POLAR and PalCare data and identified improvement opportunities. • **Population data analysis:** Evaluated gaps in demographic and service data to inform recommendations • **Prior work**

Step 4: Identifying and prioritising opportunities to improve outcomes in palliative care across the NWMPHN region

Following triangulation (Step 3), the final stage of the PCNA involved identifying opportunities to improve outcomes in palliative care and prioritising them across the region. While these opportunities may not capture activities that NWMPHN may implement, they provide an essential guiding framework for planning.

First, sets of evidence-informed opportunities were developed for each research question, all with potential to drive improvement across the three focus areas: communication and awareness, knowledge and capability, and data and equity.

Second, NWMPHN’s GCfAHPC team grouped these into high-order themes and tested the feasibility of implementation. This was essential for synthesising evidence and informing planning of potential activities, considering the program scope, availability of funding, resources, workforce and infrastructure.

Feasibility was rated on three criteria:

- **Would the activity be within the GCfAHPC program remit and scope?**
- **What is the perceived impact?** Perceived impact was assessed on the potential to solve a genuine problem, improve health outcomes and program performance, and create sustained long-term benefits.
- **What is the perceived effort?** Perceived effort was assessed on considerations for resources, capability, capacity and implementation considerations.

3.2 Key strengths and limitations

The PCNA methodology drew on diverse qualitative and quantitative sources, each offering distinct strengths while also presenting limitations.

Quantitative data

- **Strengths**: Large-scale datasets (for example, ABS Death Registrations, Census, MBS, PBS) provide robust denominators, national coverage, and the ability to analyse trends in mortality, service utilisation, and prescribing patterns. These datasets support PHN-level reporting and benchmarking across regions.
- **Limitations**: Many datasets (for example, POLAR, ABS Death Registrations) lack palliative care-specific identifiers. Equity indicators are often incomplete or binary, limiting visibility of populations such as LGBTIQ+, people with disabilities, those experiencing homelessness, and culturally diverse groups.

Qualitative data

- **Strengths**: High-quality evidence systematic reviews and conceptual frameworks (such as COM-B, TDF) provide thematic insights into systemic challenges and opportunities in palliative care.
- **Limitations**: The rapid review methodology was constrained by time and resources limitations, potentially biasing findings toward selected search strategies or missing emerging or unpublished evidence. Evidence comes from diverse research methods and settings, which may limit generalisability at the PHN level.

Consultations and survey

- **Strengths**: Semi-structured interviews and internal subject-matter expert consultations capture lived experiences, practical challenges and local context. This qualitative input complements literature and quantitative data, enhancing triangulation and informing feasible, contextually relevant strategies.
- **Limitations**: Small sample sizes (for example, n=14 for primary care interviews; n=32 for Death Literacy survey) restrict representativeness. Participation limited to primary care workforce. Patients and families/carers were not consulted. Selection and response bias are possible among external respondents (such as those with a strong interest in palliative care) and internal sources (such as NWMPHN staff perspectives). Findings may not generalise beyond the local context.

A brief description of the main sources and a statement about quality are in Appendix D: Detailed list of data sources and limitations.

3.3 Ethical considerations

The ethical considerations for each key activity in the PCNA methodology are outlined in **Table 6**.

Table 6. Ethical considerations for internal and external consultations

Group	Ethical considerations
Primary care provider consultations	• **Plain language statement:** Provided to all participants to ensure clarity and understanding of the project purpose and their involvement. • **Participant reimbursement:** Each participant compensated $150 per hour in accordance with the NWMPHN Stakeholder Reimbursement Policy. • **Summary of insights:** Participants received an email summarising key findings and messages in high-level points, enabling them to confirm that their input had been accurately captured and interpreted, and providing an opportunity for further clarification if needed.
Internal NWMPHN staff consultation	• **Mitigating bias:** Literature was used to identify key data gaps and challenges affecting diverse populations and groups. These findings were then validated by NWMPHN staff based on their professional experience.
Death Literacy Index survey	• **Survey format:** A short version of the Death Literacy Index (two-minute survey) was adopted. • **Incentive:** Respondents were entered into a draw to win a $100 gift voucher. • **Distribution channels:** The survey was disseminated broadly to reach diverse audiences, including: - Primary Health Care Improvement and Aged Care teams to share with their stakeholders - Older Adults Expert Advisory Group (EAG) and General Practice EAG - Primary Care Voices mailing list - Newsletters: Network News, GP Newsletter, GP CPD Newsletter - 2024-25 GCfAHPC project participants - Basecamp forums for Practice Nurses and Practice Managers - Social media: paid LinkedIn campaign throughout October - Project stakeholders, including Palliative Care Consortium and Palliative Care ECHO project - Consultation interview participants, with a request to share with colleagues

4. Findings

4. Findings

4.1 Research question 1: Communication and awareness

In palliative care, effective communication is essential to meet the needs and preferences of patients and their relatives. However, health care professionals frequently indicate that conversations about life-limiting illness, death and dying are a challenging aspect of care delivery.

Situation

In palliative care, communication can include discussing prognosis and end-of-life issues, providing emotional support, eliciting values and goals, and ACP (CareSearch, 2024). These discussions require effective communication that enables information exchange, shared decision-making, and strong relationships. The outcomes of these discussions, whether positive or negative, influence the timing and continuity of person-centred care and how well care is coordinated between generalist and specialist services. Communication is recognised by the Australian Commission on Safety and Quality in Health Care (ACSQHC) as a key safety and quality issue in the health care context (ACSQHC, 2020). It follows that improving the effectiveness of communication could lead to more timely and holistic palliative care.

Efforts to improve the effectiveness of communication within Australia's health care system are prevalent (ACSQHC, 2020). NWMPHN has previously done work to understand key issues in communication from a quality improvement (QI) perspective, including a palliative care spotlight project in 2025.

This project aimed to understand how to improve communication across and between systems, largely indicating the importance of digital infrastructure to support information sharing. The pilot revealed that QI support led to improvements in general practice teams' knowledge, processes and skills in two crucial domains: ACP and end-of-life conversations.

However, communication continues to be a persistent issue, including between health care professionals and their patients and between care providers with shared patients. These ongoing challenges were highlighted in consultations with Clinical and Community Council and expert advisory group members.

Complication

Health care professionals can only provide timely and holistic palliative care if they are aware of the needs, goals, and preferences of patients and their relatives or carers. This is often the outcome of effective communication; the ACSQHC (2020) describes effective communication as coordinated, continuous two-way or multi-way exchanges of accurate and timely information, while Engel et al. (2023) extend this definition for palliative care, including equality between communication partners, addressing physical, psychological, social, and spiritual needs, and fostering care that is perceived to be appropriate and safe by patients and their relatives or carers.

However, communication is complex and not inherently effective. In palliative and end-of-life care, this complexity is compounded by difficult conversations about death and dying, and varied values and beliefs shaped by cultural diversity and death literacy. Communication theory and research posit the importance of adapting communication styles to the preferences of the person receiving the information (Giles et al., 2023; Momand et al., 2022). Applying a 'needs assessment lens' (Smart, 2019) suggests a need exists in the gap between current communication practices and the ideal conditions, particularly those described by Engel et al. (2023). Hence, people's communication preferences may represent a key unmet need in this context.

Question

To address this gap, **Research Question 1** explores communication preferences and the impact of these on timely, holistic care:

Communication and awareness: What are the communication preferences of patients with life-limiting illness and their relative/carers and how does the health provider awareness of these preferences influence the delivery of holistic palliative care across illness trajectories?

Important data limitation

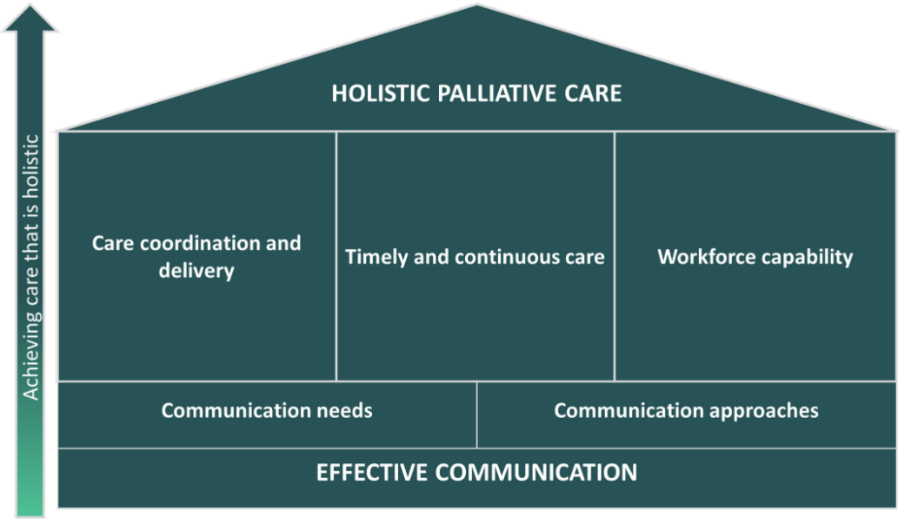
- **Patients and their families or carers were not directly consulted as part of this process**.
  A literature review was undertaken to gain a broad understanding of patient and family-carer perspectives.
- **Contextual variability**. Although the review focused on robust literature, included studies were drawn from Australian and international contexts, spanning diverse health care settings and study designs. While communication principles often have broad applicability, findings may differ when specifically examined within general practice settings.
- **Community-level variation**. Literature reviews provide a useful foundation for understanding population needs, but variability at the community level is to be expected. Direct engagement through community consultations is essential to capture perspectives, particularly those of underrepresented groups, and to address gaps in the evidence base. As a result, the findings may not be generalisable across all population groups.
- **Framework selection**. The SPIKES framework (Baile et al., 2000) is a six-step model for clear, empathetic, and tailored conversations. It was used to present findings in a practical format, because it has been tested across multiple contexts and supports potential generalisability. However, this choice does not constitute an endorsement of SPIKES over other evidence-based resources, such as Palliative Care Australia's Dying to Talk Together resource.

Communication as the foundation of holistic palliative care

Evidence from the literature, supported by consultations with primary care providers, indicates that communication is the foundation of holistic palliative care.

The core findings are illustrated by **Figure 16**. Effective communication, understanding communication needs and applying appropriate approaches underpin all aspects of care delivery. Building on this foundation are three essential pillars: care coordination and delivery, timely and continuous care, and workforce capability. Together, these enable a person-centred approach that supports patients and families throughout the trajectory of life-limiting illness to end-of-life.

Figure 16. Conceptual framework of research question 1 findings



Communication as enabler and barrier

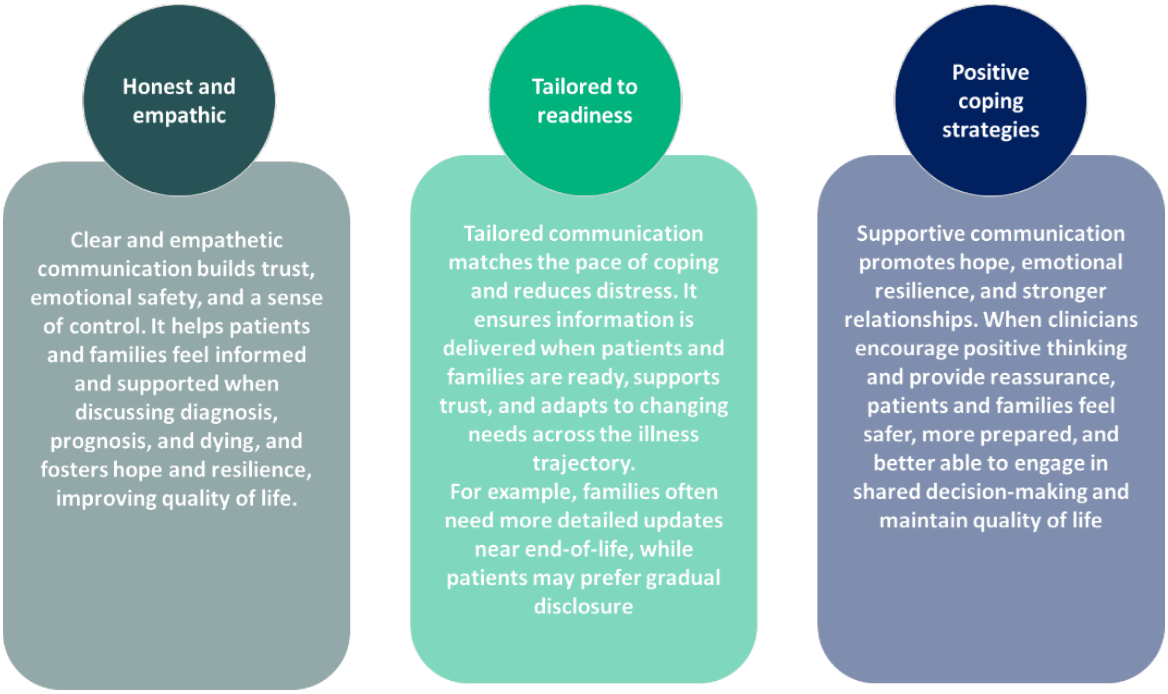
Consultations mirrored literature, with the effectiveness of communication consistently emerging as both an enabler and a barrier to delivering holistic palliative care.

- **Care coordination and delivery**. Consultation and literature findings revealed that effective communication underpins the coordination of holistic palliative care (Pun et al., 2023). In consultations, primary care providers emphasised that effective communication is essential for connecting specialists, palliative care teams and families, adapting to cultural contexts, and eliciting preferences for care and place of death. The literature also highlighted the consequences of poor communication (Langley et al., 2022; Pun et al., 2023). Consultations echoed this, with GPs and nurses noting that when communication breaks down, continuity and patient-centred care suffer, citing time, funding constraints, and varied death literacy as barriers.
- **Timely and continuous care**. Consultations and research identified communication as central to timely ACP and continuous care. GPs note that conversations were often missed, delayed or otherwise avoided due to emotional complexity, leading to reactive ACP and fragmented care. Literature shows that trusting relationships and shared systems enable early engagement, while avoidance and poor information flow cause late-stage planning and poor transitions (Ekberg et al., 2021; Rhee et al., 2020; Pocock ., 2024). This finding builds on information from members of the NWMPHN Older Adults EAG, and Clinical and Community Councils. All agree that the lack of ACP is a persistent issue and raised the importance of early conversations with family and patients, rather than waiting until crisis point.
- **Workforce capability**. Initiating and navigating sensitive conversations is a defining capability in palliative care, and crucial for effective communication (Peerboom et al., 2023; Schallmo et al., 2019). Consultations reinforced this, with primary care providers highlighting death literacy, empathy, and listening skills as core capabilities that influence the effectiveness of communication. Without these, barriers such as fear of causing harm and limited palliative care knowledge persist (Peerboom et al., 2023; Poveda-Moral et al., 2021; Selman et al., 2017). Consultations reinforced that structural enablers like training and integrated systems support these capabilities, while time-poor environments driven by funding constraints were a major obstacle.

Communication preferences of patients and families

Patients and families prefer communication that is clear, honest, empathetic, tailored to emotional readiness, and supportive of coping strategies. **Figure 17** outlines them and their role in fostering effective communication. Ineffective communication often stems from limited awareness of these preferences. When these preferences are unmet, communication is less likely to succeed (Giles et al., 2023).

Figure 17. Communication preferences of patients with life-limiting illnesses and their families and carers



Honest and empathetic

Clear and empathetic communication builds trust, emotional safety, and a sense of control. It helps patients and families feel informed and supported when discussing diagnosis, prognosis, and dying, and fosters hope and resilience, improving quality of life.

Tailored to readiness

Tailored communication matches the pace of coping and reduces distress. It ensures information is delivered when patients and families are ready, supports trust, and adapts to changing needs across the illness trajectory.
For example, families often need more detailed updates near end-of-life, while patients may prefer gradual disclosure

Positive coping strategies

Supportive communication promotes hope, emotional resilience, and stronger relationships. When clinicians encourage positive thinking and provide reassurance, patients and families feel safer, more prepared, and better able to engage in shared decision-making and maintain quality of life

Figure note: This figure synthesises findings from the following sources: [1]Honest and empathetic (Engel et al., 2023; Peerboom et al., 2023; Velić et al., 2023); [2]Tailored to readiness (Anderson et al., 2019; Ekberg et al., 2021; Nagelschmidt et al., 2021; Rhee et al., 2020); [3]Positive coping (Engel et al., 2023; Peerboom et al., 2023; Velić et al., 2023).

Frameworks to support effective communication

Individual and system-level barriers often prevent primary care practitioners from fully applying these approaches. Explored earlier in this report, awareness and death literacy is a common individual-level barrier. As shown in Figure 15, there were deficiencies in factual and community knowledge about the death system. There were also gaps in awareness of community services among the 32 health care respondents interviewed. During consultations, providers expressed a similar sentiment about knowledge gaps among patients and family. This was also cited by the expert advisory group and Clinical and Community Council members.

The most persistent system-level barriers for communication included time and funding model constraints. These interact to create an environment that does not foster conditions acceptable for complex and difficult conversations that the end-of-life and palliative care environment requires. Prior QI work by NWMPHN demonstrated that practical strategies can address some of these by successfully incorporating ACP discussions into health assessments, and using patient-facing resources helped clinicians initiate sensitive conversations more confidently.

However, the current findings also demonstrate that effective communication also works at the individual level. The findings highlight that health care professionals can improve the effectiveness of communication when they tailor conversations to the communication preferences of their patients, and their family and carers (Momand et al., 2022). During consultations, primary care providers consistently recognised that honest, empathetic, and tailored communication was central to quality palliative care during consultations and highlighted improving communication approaches as a key opportunity. Providers demonstrated a strong understanding of the importance of meeting communication preferences and emphasised adapting approaches to patient and family contexts, including diagnosis, culture and care setting.

For example, two GPs described their roles as:

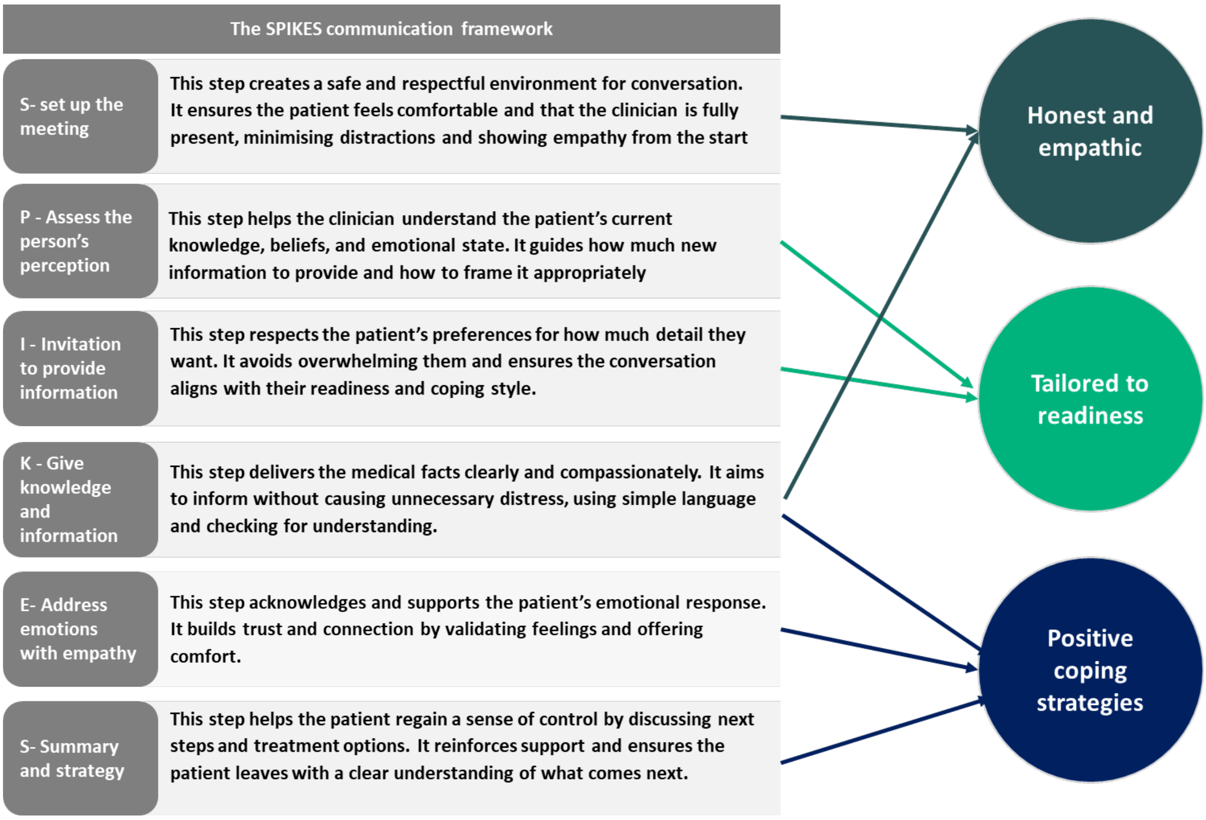
- “To inform [patients/family/carers] and then empathetically express our concerns and then their concerns and answer their questions.”
- To support coping by “giving them a secure environment to just ventilate what they're going through.”

While no single solution exists, the SPIKES framework (Baile et al., 2000) provides practical guidance for structuring these discussions. As illustrated in **Figure 18**, the SPIKES framework addresses the three primary communication preferences of patients, families and carers by promoting transparent, empathetic, and tailored communication. It structures conversations to assess patient understanding, pace disclosure to coping capacity, validate emotions and provide clear next steps, fostering trust, resilience, and collaborative care planning.

Despite this awareness, systemic barriers often leave these communication preferences unmet. Time and funding constraints limit opportunities for sensitive conversations, while cultural and linguistic complexities make tailoring communication more challenging in resource-constrained environments. Fragmented information sharing between secondary providers further disrupts continuity, leaving GPs without the context needed for honest, well-informed discussions with their patients.

The current findings highlight the importance of embedding system-level enablers that sustain conversations beyond individual clinician effort. These include integrated workflows and continuous quality monitoring to ensure ACP discussions become a routine part of care. Embedding ACP conversations within multidisciplinary teams and strengthening cross-sectional collaboration and communication emerged as opportunities for broader application.

Figure 18. SPIKES communication framework in clinical practice mapped to communication preferences



The SPIKES communication framework	
S- set up the meeting	This step creates a safe and respectful environment for conversation. It ensures the patient feels comfortable and that the clinician is fully present, minimising distractions and showing empathy from the start
P - Assess the person’s perception	This step helps the clinician understand the patient’s current knowledge, beliefs, and emotional state. It guides how much new information to provide and how to frame it appropriately
I - Invitation to provide information	This step respects the patient’s preferences for how much detail they want. It avoids overwhelming them and ensures the conversation aligns with their readiness and coping style.
K - Give knowledge and information	This step delivers the medical facts clearly and compassionately. It aims to inform without causing unnecessary distress, using simple language and checking for understanding.
E- Address emotions with empathy	This step acknowledges and supports the patient’s emotional response. It builds trust and connection by validating feelings and offering comfort.
S- Summary and strategy	This step helps the patient regain a sense of control by discussing next steps and treatment options. It reinforces support and ensures the patient leaves with a clear understanding of what comes next.

Figure note: Adapted from the SPIKES framework (Baile et al., 2000). This figure was developed using a resource developed by End-of-Life Essentials and CareSearch for guidance.

Opportunities to improve communication outcomes in the delivery of palliative care

Effective communication is fundamental to quality palliative care, yet challenges remain in consistently meeting the preferences of patients, families, and carers. **Table 7** outlines opportunities, actions, and their expected impacts to enhance communication outcomes in primary care settings, supporting more empathetic, transparent, and patient-centred care.

Table 7. Opportunities to improve communication outcomes in palliative care

Key opportunities and actions	Purpose and expected impact
Deliver awareness raising campaigns for community and primary care teams.	Improve understanding of palliative care and ACP among health professionals and the community, supporting timely initiation of conversations.
Provide general practice teams with patient resources to prompt ACP and palliative care discussions.	Reduce the burden of initiating difficult conversations and improve the timeliness and quality of these discussions.
Develop quality improvement initiatives targeting communication and collaboration in palliative care.	Embed the use of resources and strategies that support effective patient communication, improve workflows, and enhance communication across care settings.
Promote availability of services that support primary care professionals, families, and carers who require further information.	Increase awareness and use of specialist advice and secondary consult services.
Increase awareness of effective interpreter use in palliative care.	Improve communication with patients with limited English proficiency and ensure informed decisions about interpreter use. Reduce risks when family interpreters are used and enhance interaction quality and patient support.
Build cultural competency in primary palliative care.	Share culturally safe care education and resources to improve awareness, communication and care for diverse and vulnerable groups.

4.2 Research question 2: Knowledge and capability

GPs, practice nurses, and primary care teams are often the first point of contact for patients with palliative needs. Their role is pivotal in ensuring continuity of care, early identification of needs, and coordination across services. However, primary care providers face myriad challenges in delivering best practice palliative care.

Situation

Palliative care is a critical component of holistic health care, yet access to timely, high quality, and culturally safe palliative care remains inequitable across Australia. Despite national strategies and growing awareness, many patients, particularly those in rural, culturally diverse, or socioeconomically disadvantaged communities, continue to experience significant barriers to receiving appropriate end-of-life care. These disparities are compounded by workforce shortages, fragmented care pathways, and limited integration between generalist and specialist services (Javanparast et al., 2022).

Complication

As highlighted in a recent qualitative study, Australian GPs face multiple challenges in delivering best practice palliative care (Herrmann et al., 2019). These include emotional burden, lack of formal training, unclear team roles, and systemic issues such as inadequate funding and poor communication infrastructure between care providers. Similarly, nurses in palliative care settings struggle with implementing evidence-based practice (EBP) due to time constraints, limited access to resources, and resistance to change, both personal and organisational (Dakka, 2022)

Policy analysis further underscores the systemic nature of these challenges. While equity is increasingly recognised in national and state-level palliative care strategies, implementation remains limited. Cultural and ethnic considerations such as language barriers, mistrust of Western medicine, and lack of culturally appropriate models are often acknowledged but not adequately addressed in practice (Javanparast et al., 2022). There is a clear need for stronger community engagement, inter-sector collaboration, and investment in culturally inclusive care models.

Question

Given the complexity and emotional intensity of palliative care, especially in primary care settings, there is a pressing need to understand the behavioural drivers that influence practice. This PCNA aims to better understand these challenges and identify how we can better support the delivery of compassionate, inclusive, and evidence-informed palliative care. It asks:

Knowledge and capability: What knowledge gaps, misconceptions and attitudinal barriers exist among GPs, practice nurses and practice teams, and what practical strategies could improve them?

Barriers and enablers to delivering best practice palliative care

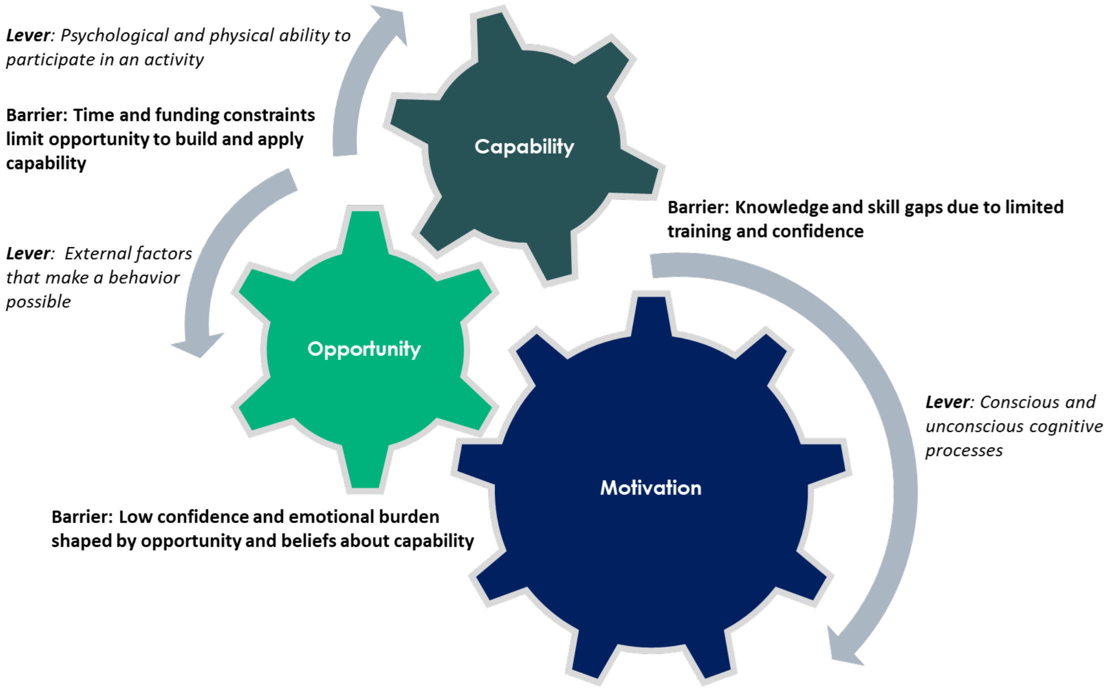
This section uses the Capability, Opportunity, Motivation – Behaviour (COM-B) model of behaviour change (Michie et al., 2011) as a guiding framework, which cites capability, opportunity, and motivation as three key factors capable of changing behaviour. Building on the COM-B, enablers and barriers were organised according to domains of the Theoretical Domains Framework (Atkins et al., 2017; TDF), which encompasses a wide range of factors that can influence behaviour.

Mapping literature to the COM-B and TDF domains provided a robust understanding of how capability, opportunity, and motivation influence the delivery of best-practice care (see **Table 8**). This revealed enablers and barriers for various behavioural determinants of capability, opportunity, and motivation, such as knowledge and social influences. It also highlighted behaviour change strategies that have been applied to the behavioural determinants of capability, opportunity, and motivation.

Triangulating this with consultation findings (Appendix F) and a death literacy index survey (**Figure 15**) revealed that opportunity and motivation often act as barriers or enablers. For instance, even when capability exists, limited opportunity (for instance, in time or resources) or low motivation (such as poor confidence) can impede change. This dynamic was particularly evident in the distinct barriers faced by GPs compared to nurses, underscoring the need for tailored strategies that address the unique behavioural levers within each group. Consultations also demonstrated which strategies primary care providers consider most effective.

Figure 19 illustrates the result of triangulation, highlighting that while modifying a single factor, such as capability, can change behaviour, it is rarely shaped by one factor alone. These are various determinants of behaviour, and these can act as unique barriers and levers for capability, opportunity, and motivation.

Figure 19. Conceptual framework of research question 2 findings



While knowledge and skill gaps were evident, these were largely driven by a lack of physical opportunity, particularly funding and time constraints. These limitations not only restricted practitioners' ability to build capability but also contributed to emotional strain and reduced confidence in delivering holistic, patient-centred care.

Using the COM-B model, consultations with primary care providers reinforced that palliative care delivery is shaped by a complex interplay of these components. Key insights include (see Appendix F for more detail):

Capability. Knowledge and skill gaps were most pronounced in areas such as ACP, opioid prescribing, culturally responsive communication, and care coordination for non-cancer diagnoses. Practitioners frequently cited a lack of formal training and certification as a key driver. In some cases, GPs described avoidance or withdrawal after referring patients to palliative care teams, stating they do so "because [they] don't want to bother them."

> *"The majority of GPs don't have a lot of [palliative care] training ... and a lot of them have picked it up indirectly." GP*

Opportunity. Practitioners consistently reported insufficient opportunity, particularly in terms of environmental context and resources. The most significant barrier was lack of funding. Inadequate MBS funding to effectively facilitate complex care constrained the ability to spend adequate time with patients and families or carers, engage in multidisciplinary care, participate in training, and coordinate services. These limitations directly impacted capability-building and reinforced negative beliefs about competence, contributing to emotional strain.

> *"The idea of holistic care is not funded in any way, shape or form." Community health nurse*
>
> *"Staff recognition, the peer mentoring, the debriefing ... it's just almost impossible because we are so bound by time constraints." GP*

Motivation. Motivational barriers were primarily linked to low confidence, stemming from feeling unprepared (due to knowledge and skill gaps) and unsupported (due to time and funding constraints). For example, initiating conversations about death and dying was described as particularly challenging. In the context of ACP, a practice nurse noted: *"It's a hard question to ask some people ... especially because it makes them think about end of life."* Emotional burden was also a key factor, with practitioners expressing grief, guilt, and fear of causing harm, especially when unable to provide the care they believed was needed.

> *"We hear that they passed... then we just think... we just haven't done enough for that patient." GP*

Table 8. Detailed analysis of behavioural components influencing palliative care delivery using the COM-B model and TDF

COM-B domain	TDF domains	Barriers	Enablers	Potential strategies and intervention functions
Psychological capability	**Knowledge**	• Limited training in palliative care and ACP for GPs, nurses, and allied health professionals • Lack of cultural competence and uncertainty about customs • Lack of knowledge of funding and billing systems	• Staff interest in learning • Availability of structured resources (ACP toolkits, CareSearch, Advance Project) • Feedback from patients and families reinforces learning	**Education, training, enablement:** • Develop targeted training modules on ACP, cultural competence, and billing systems • Create quick-reference guides • Embed resources in electronic medical records (EMR)
	Skills	• Lack of confidence to initiate ACP and end-of-life conversations • Junior and casual staff face competing training demands • Difficulty navigating cross-cultural discussions	• Peer mentoring and role-modelling • Training builds communication skills • Role-specific professional development opportunities	**Training, modelling, enablement:** • Use role-play scenarios and peer mentors • Deliver case-based workshops • Provide practice-specific toolkits
	Behavioural regulation	• Inconsistent use of ACP or palliative care tools • Limited capacity for staff to apply skills and affect practice change after training	• Ongoing reflective practice • Prompts and reminders in workflows • Embedding ACP into existing assessments	**Enablement, environmental restructuring:** • EMR prompts • Create audit-feedback cycles • Implement regular reflective sessions
Physical opportunity	**Environmental context and resources**	• Fragmented care pathways and poor EMR integration • Workforce shortages, especially in rural and remote areas • Lack of referral options • Busy practices, little private space • Limited funding structures	• Telehealth infrastructure • Multidisciplinary team (MDT) models • Rural GPs and nurses provide continuity • Funding programs exist	**Environmental restructuring, enablement, service provision:** • Expand funding for MDT case conferences • Expand telehealth palliative consults • Redesign clinic space for privacy • Improve EMR integration between care providers
Social opportunity	**Social Influences**	• Limited interpreter access, reliance on family • GP and practice manager buy-in inconsistent	• Interpreter services • Cultural liaison staff • Strong partnerships with communities	**Enablement, modelling, persuasion:** • Expand interpreter access • Train staff in interpreter use • Employ Aboriginal health workers • Share success stories of GP leadership
Reflective motivation	**Beliefs about capabilities**	• Practitioner anxiety and low confidence • Some clinicians don't see ACP as "their role"	• Nurses, carers motivated by holistic values • Training and mentoring builds confidence	**Training, persuasion, modelling:** • Highlight role clarity in job descriptions • Use peer champions • Showcase patient outcomes

COM-B domain	TDF domains	Barriers	Enablers	Potential strategies and intervention functions
	Professional role and identity	- Ethical and value conflicts (Western autonomy vs family-centred models)	- Patient-centred philosophy encourages flexibility - ACP recognised as holistic care	**Education, modelling, persuasion:** - Provide cultural safety training - Share case studies of family-centred ACP - Use clinical champions
	Intentions and goals	- Patients and families reluctant due to cultural taboos, low literacy, competing priorities	- GPs' long-term trust relationships - Positive patient outcomes reinforce commitment	**Education, persuasion, incentivisation:** - Run public campaigns to normalise ACP - Tailor communication tools for low literacy - Recognise and celebrate ACP champions
Automatic motivation	**Emotions**	- Emotional burden of end-of-life care - Fear of offending or causing harm	- Positive family experiences - Supervision and debriefing supports staff	**Enablement, modelling, training:** - Establish debrief and support groups - Normalise end of life discussions with scripts - Provide wellbeing resources

Table note: This table synthesises evidence from the following sources (Burke et al., 2023; Dakka, 2022; Green et al., 2018; Herrmann et al., 2019; Javanparast et al., 2022; Karacsony et al., 2024; van Gaans et al., 2022)

Role-specific perspectives on ACP and palliative care strategies

While GPs and nurses recognise the value of ACP and palliative care, their experiences highlight different points of pressure within the COM-B system. Reflecting these enablers and barriers, GPs and nurses hold distinct views on the effectiveness and feasibility of strategies to build capability for delivering ACP and palliative care.

The literature highlights that GPs are more influenced by systemic factors and role clarity, including time pressures, remuneration mechanisms and medico-legal concerns. Nurses, on the other hand, are more affected by workforce support and the emotional and relational dimensions of care, such as the need for mentoring, debriefing and holistic approaches.

During consultations, participants ranked 10 strategies proposed to address these barriers on two dimensions: perceived effectiveness (impact on improving ACP and palliative care) and perceived feasibility (ease of implementation). The rankings were analysed with qualitative findings from discussions across two roles: GPs and nurses.

Table 9 shows these results, insights included:

- Strategies that require systemic integration and coordination (for example, MDT case conferencing, peer mentoring) were rated effective but less feasible. Strategies that fit into existing workflows or technology (such as telehealth and care planning templates) were seen as more feasible. Strategies tied to cultural or relational care (such as culturally safe care, staff recognition) were valued differently by roles and faced feasibility barriers due to resource and awareness gaps.
- MDT case conferencing, role-specific training and shared templates and tools were perceived as most effective and mostly feasible. MDT case conferencing "works well" but requires significant coordination and creates an administrative burden that is not funded. Role-specific training was seen as valuable but constrained by time and resource limitations, with suggestions for technology-based solutions such as virtual reality simulations. Shared care planning templates were considered helpful for reducing duplication, but participants raised concerns about interoperability and the risk of adding to provider workload.
- Peer mentoring and culturally safe care were generally seen as less feasible, largely due to significant implementation barriers. Peer mentoring was described as "pretty impossible" due to time constraints and lack of compensation, despite GPs valuing it highly. Culturally safe care was seen as extremely important but considered difficult to implement due to limited awareness of services, such as navigators, and time pressures during consultations.
- GPs prioritised clinical coordination strategies such as MDT case conferencing and peer mentoring. These supportive strategies reflect systemic pressure, time limitations, funding models and medico-legal concerns that shape their individual capability and opportunity to engage in ACP. GPs emphasised the need for clearer role coordination and practical solutions to reduce administrative burden.
- Nurses emphasised relational strategies, including cultural safety and staff recognition. Nurses were slightly more optimistic about the feasibility of these, especially for cultural and staff support strategies. They also prioritised strategies such as debriefing and cultural care, suggesting a stronger focus on workforce wellbeing and patient-centred approaches. Nurses highlighted the emotional burden of care and the importance of holistic approaches, noting that structured recognition and support could improve morale and resilience.

Table 9. Strategies for ACP and palliative care delivery by effectiveness and feasibility

Potential strategy	Short description	Effectiveness	Feasibility
MDT case conferencing	Role clarity and protected time for team-based palliative care and ACP.	Widely considered effective for improving care coordination. Works well for improving care coordination when organised effectively.	Challenging due to scheduling, administrative burden, and unclear roles. Requires strong integration and specialist involvement.
Role-specific training with case-based scenarios	Practical training workshops with real-life palliative care and ACP scenarios.	Seen as highly valuable for building capability. Participants highlighted the value of interactive, scenario-based learning that reflects real-world challenges.	Limited by time, funding, and workforce constraints. Suggestions included technology-based solutions (for example, virtual reality) to make training more accessible.
Shared templates and tools	Embedding ACP prompts and templates in practice systems.	Seen as effective for reducing duplication and standardising processes, relieving patients from having to repeat their story multiple times.	Barriers include lack of interoperability across systems and risk of adding to provider workload. Must be evidence-based and save time or resources.
Telehealth consults	Accessing specialist palliative care via telehealth.	Helpful in urgent situations or when families need education. Provides access to specialist advice without requiring in-person visits. Seen as a practical solution for time-sensitive care.	Considered feasible because technology is already available and familiar, even though scheduling and specialist availability are major challenges.
Community campaigns	Normalising ACP and palliative care conversations by sharing campaign information.	Seen as useful for improving public awareness and understanding of ACP and palliative care. Helps normalise conversations and encourages early engagement. Seen as a way to provide patients with accessible information.	Feasible because GPs can distribute materials easily, though they cannot lead campaigns. These may require public health or local community involvement.
Peer mentoring	Pairing staff with palliative care or ACP champions for coaching and role-modelling.	Valued by GPs for capability building and to provide valuable practical guidance and knowledge-sharing.	Not perceived as feasible due to time constraints, lack of compensation, and shortage of specialists.
Interpreter service access	Greater awareness and use of trained interpreters for palliative care and ACP conversations.	In-person interpreters preferred over phone-based options; family members often used for simplicity and engagement.	Professional interpreters inconsistently available; cultural and religious factors can complicate communication. Inconsistent availability and cultural or religious factors complicate communication
Debriefing and support for staff	Forums and resources for staff to process emotional burden.	Acknowledged as critical for emotional wellbeing. Some practices employ private psychologists but restrict sessions due to cost.	Often occurs informally; structured support limited by cost and lack of external resources.
Staff recognition	Celebrating staff who integrate ACP, showcasing positive patient and family outcomes.	Considered important to help manage emotional burden and stress after challenging cases, but less relevant in small practices.	Informal recognition and team support often preferred over structured programs.
Culturally safe care	Accessing Aboriginal health workers or cultural navigators.	Builds trust and rapport with patients from diverse backgrounds. Family and community connections seen as effective alternatives to formal liaison officers.	Difficult to implement because of limited awareness of services, lack of liaison officers, and time pressures during consultations.

Table note: These strategies were identified across the literature (Burke et al., 2023; Dakka, 2022; Green et al., 2018; Herrmann et al., 2019; Javanparast et al., 2022; Karacsony et al., 2024; van Gaans et al., 2022).

Capability in practice: perspectives and person-centred approaches

During consultations, providers were asked to explain how they would approach two clinical case scenarios which involved complex palliative care needs.

In these discussions, GPs primarily framed their approach to holistic palliative care around communication, cultural safety and systemic barriers. In contrast, nurses focused on practical and operational aspects, including symptom management and resource coordination.

Figure 20. Case scenario 1: Elaine – advanced COPD, independent patient

CASE STUDY 1:

Advanced COPD, independent

Patient: Elaine Jones
Age: 84

Background: Retired teacher, widowed, lives alone in a small unit. Two adult children, one in Melbourne and one interstate. She is fiercely independent and values her privacy.

Medical history:

- Severe chronic obstructive pulmonary disease (COPD)
- Frequent hospital admissions for exacerbations over the past year
- Hypertension, osteoporosis
- Recently discharged after a prolonged hospital stay requiring non-invasive ventilation

Presenting situation:

> ***Elaine is attending a follow-up appointment with her GP after hospital discharge.***
>
> ***The respiratory team has documented that she is now in the terminal phase of COPD with a prognosis of less than 12 months.***
>
> ***She is increasingly breathless at rest, fatigued, and has lost weight. She uses home oxygen and has a walking frame.***

Key perspectives:

General practitioners	One emphasised autonomy and care coordination, suggesting that Elaine's independence means she likely has strong views on her care. They recommend starting with an advanced care directive and tailoring care delivery to her preferences.	"Start with whether she has an advanced care directive, whether she wants to make one … I feel that she's got a lot to say … and might already have quite clear formed thoughts in her head about end-of-life care. And I think that will be my starting point for her."
	A second GP responded to Elaine's case by sharing a similar patient experience, highlighting challenges in coordinating palliative care in regional settings. They described a COPD patient discharged with a palliative care plan from a non-local hospital and praised the hospital's proactive approach and the involvement of the community palliative care team.	"[the hospital] was very helpful … they discharged her with the palliative care community team … [which] must have had a good talk with the husband … So when she was discharged everybody went OK, it's palliative … so that was really … very, very helpful."
	A third GP highlighted the growing need to support non-cancer patients in palliative care and the importance of early referral to specialist COPD clinics.	"I can't remember the exact name [of the clinic] for advanced or terminal COPD … in the respiratory unit … people have a barrier to referring to or moving their patient towards but once they get there, because they embrace the palliative care approach, their quality of life improves."
Nurses	The nursing perspective focused on practical arrangements, environmental safety, and symptom management to support Elaine's wish to remain at home. Their approach complemented the GP perspectives by operationalising care plans and ensuring that Elaine's physical and social needs are met through coordinated, multidisciplinary support.	"If she wishes to stay at home as long as possible then we would try and optimise that by doing breathlessness management plans, fatigue management plans, supporting her with My Aged Care for cleaning or personal support."

Conclusion: Elaine's case

Approaches emphasised autonomy, home-based support, and service coordination. This case demonstrated that a holistic approach to Elaine's care relied on proactive service engagement and shared care models to enable early identification, coordinated discharge planning, and strong community-based support.

Figure 21. Case scenario 2: Ahmed – advanced lung cancer, CALD background

CASE STUDY 2:

Advanced lung cancer, Egyptian background

Patient: Ahmed El-Sayed

Age: 65

Background:

Originally from Egypt, lives in Melbourne with his wife and adult son. Speaks Arabic and limited English. His son often accompanies him to appointments and helps interpret. He is a devout Muslim.

Medical history:

- Diagnosed with stage IV non-small cell lung cancer 14 months ago
- Completed chemotherapy and immunotherapy; recent scans show disease progression
- Increasing breathlessness, fatigue, and weight loss
- No prior mental health history

Presenting situation

> ***Ahmed is attending a follow-up appointment with his GP after seeing his oncologist, who has confirmed that the cancer is no longer responsive to treatment.***
>
> ***He has been referred to palliative care. His son is present and appears protective, occasionally answering on his behalf.***

Key perspectives:

General practitioners	One GP emphasised the importance of using interpreters during ACP and ensuring that Ahmed's wishes were accurately captured in more complex family contexts. They also highlighted the need to understand religious and cultural practices such as burial arrangements, and ensure that culturally appropriate support was available to the family.	"Having an interpreter for the advanced care plan … it's really important that it's the patient's wishes, not what the family says. … Culturally appropriate support for the family is required [and] linking them in with … networks in the local area would very useful."
	Another GP described the underutilisation of interpreters a systemic barrier for patients like Ahmed. They proposed a staged approach that prioritised building trust and gradually introducing interpreter-supported consultations.	"The number one reason that we get from patients who transfer here from another service is that they didn't use an interpreter. I think we need to negotiate here between the patient and the family members and have a blended system … perhaps for the first consultation … let the son do the talking … once the trust is built [ask] for the next time … 'why don't I see your dad first by himself'?"
	A third GP reflected on the value of joint visits with palliative care nurses to support family discussions and build trust, especially in culturally sensitive cases.	"The most helpful thing was actually timing my visit with the palliative care nurse visit, just to talk to the family and have that little conference. It's really valuable."
Nurses	The nurse practitioner primarily described culturally responsive strategies such as ensuring health literacy materials are available in Arabic, confirming burial arrangements, assessing patient understanding of prognosis, managing symptoms such as breathlessness, fatigue, and weight loss, and engaging psychosocial supports such as volunteers for life stories.	"Making sure that the health literacy for the actual patient has been delivered in Arabic… and he's aware of his prognosis."

Conclusion: Ahmed's case

The palliative approach centred on cultural safety, interpreter use, and family dynamics. Responses highlighted that holistic care for Ahmed required structural supports alongside nuanced, culturally responsive communication strategies.

Opportunities to build knowledge and capability in palliative care

Building capability in primary care is essential to delivering high-quality, evidence-based palliative care. The opportunities in Table 10 **highlight strategies and initiatives designed to support clinicians, streamline processes, and enhance patient and family outcomes.**

Table 10. Opportunities to build knowledge and capability in palliative care

Opportunities and actions	Purpose and expected impact
Promote existing capability-building opportunities and resources, particularly those available in self-directed or flexible formats.	To increase uptake of evidence-based education and resources, enabling primary care team members to build capability in a flexible way, reducing the impact of resource limitations on attendance.
Encourage participation in low-resource, low-commitment peer learning and mentoring opportunities, such as communities of practice (for example, University of Queensland's Palliative Care ECHO), the Victorian Palliative Care Advice Service, and the Victorian Virtual Specialist Consults service.	To provide accessible avenues for shared learning and professional support without significant time or financial burden.
Develop local capability-building activities where gaps exist in education offerings.	To address unmet educational needs and support local delivery of evidence-based palliative care practices.
Support uptake of e-referrals and digital health initiatives aiding communication between generalist and specialist palliative care.	To streamline communication processes, reducing administrative workload and time demands. Improved e-referral integration ensures relevant fields are auto-filled, enhancing the quality and completeness of referrals to community palliative care services. Improved communication between providers will facilitate continuity of care, prompt access to key information, and clear roles and responsibilities for all practitioners involved in a patient's care.
Support increased use of My Health Record for document sharing (for example, uploads of ACPs and patient summaries).	To improve system integration and interoperability across general practice software, PalCare, and My Health Record, ensuring timely access to key documents across care settings. A PalCare patient summary function is expected 2026.
Share case studies of positive patient and family experiences.	To demonstrate the real-world impact of timely, quality care and provide relatable examples for practitioners, reinforcing relevance to their work.
Promote support strategies for primary care staff, such as debriefing tools and self-care resources.	To recognise and mitigate the emotional burden of delivering palliative care, supporting staff wellbeing and sustained high-quality care delivery.
Disseminate information about billing options and care models.	To increase awareness of available billing pathways, helping overcome barriers related to effective MBS use in primary care.
Enhance communication between care providers, including shared patient information, to enable multidisciplinary care coordination.	To improve collaboration between primary and community palliative care services, ensuring seamless, patient-centred care delivery.

4.3 Research question 3: Data and equity

Despite ongoing initiatives to promote equity in palliative care, gaps in collecting and applying cultural, linguistic, and diversity data remain, limiting the ability to provide care that is genuinely person-centred.

Situation

NWMPHN serves a highly diverse population, as detailed earlier in **Section 2.1** of this report. Care that is individualised and culturally appropriate can improve quality of life for the person receiving palliative care and their family (Lambert et al., 2025). However, the barriers to accessing timely, inclusive and coordinated palliative care are often compounded for people who experience multiple, intersecting forms of disadvantage (Australian Healthcare Associates, 2019). Delivering person-centred care, outlined in Priority 1 of Victoria's end-of-life and palliative care framework (DoH, 2016), requires a deeper understanding of the delivery, uptake, and palliative care needs and preferences of those from diverse populations (Australian Healthcare Associates, 2019).

Collecting relevant data concerning demographics and equity creates "a baseline from which to be able to measure service accessibility and design services that meet the needs of local consumers" (Centre for Cultural Diversity in Ageing, 2020). Within the NWMPHN region, most available palliative care data is sourced from hospital and specialist services, with notable gaps in non-admitted hospital services, aged care settings, and general practice. For example, there is no routine collection of palliative care data by GPs, partly due to the absence of a dedicated MBS item. The NWMPHN GCfAHPC program team describes the current state of palliative care data as like "many pieces of a puzzle that need to be pieced together".

Complication

Several persistent complications undermine the effective capture and application of cultural, linguistic, and other diversity factors in planning. There is no single, unified source for palliative care data, fragmenting data systems. Most available palliative care data in the NWMPHN region is sourced from hospitals and specialist services, leaving substantial gaps in non-admitted hospital services, aged care, and general practice (Apex Consulting, 2018). Data quality and completeness varies significantly, influenced by practice workflows, software usability, and the capacity of general practitioners to code and report accurately. Data quality improvements are often viewed as "a nice to have, not a need to have," with few incentives or little capacity for practices to prioritise reforms.

Demographic data, such as country of birth, ethnicity, and LGBTIQ+ status, are inconsistently captured or only recorded in free text, leading to incomplete and sometimes misleading data (Lambert et al., 2025). Diverse populations are frequently missing or inaccurately represented in datasets due to collection barriers, patient reluctance to disclose sensitive information, and lack of standardised workflows (Australian Healthcare Associates, 2019; Lambert et al., 2025).

The absence of granular, comprehensive data makes it difficult for NWMPHN to measure service accessibility, identify gaps, and tailor programs to local consumer needs, ultimately limiting the region's ability to deliver truly person-centred and equitable palliative care.

Question

Research question 3 focuses on how gaps in palliative care data affect NWMPHN's ability to plan and deliver equitable, person-centred care. It examines challenges in capturing cultural, linguistic and other diversity factors, and asks:

Data and equity: What gaps and challenges in capturing cultural, linguistic, and diversity data limit palliative care planning, and what practical strategies can improve data quality, integration, and equity to support person-centred care?

Primary and specialist data systems for palliative care planning

NWMPHN has opportunities to strengthen access to palliative care data and deepen understanding of the sector within the region. Two systems were identified as underutilised sources of insight: GP data collected by Outcome Health's POLAR platform and specialist data collected through PalCare Australia's PalCare software.

POLAR

POLAR is a population health analytics tool adopted by NWMPHN in July 2025. It organises and visualises de-identified data from approximately 425 general practices (around 80 per cent of the region) collected through their practice management system (PMS).

Data quality within POLAR varies based on the PMS used by practices, though around 95 per cent of them operate on Best Practice or Medical Director. POLAR is used across multiple PHNs, and while its main interface cannot be customised, NWMPHN maintains an active feedback channel with Outcome Health, and other PHNs, to contribute to improvements.

The shift from NWMPHN's previous system to POLAR has brought important capabilities, including the ability to code free-text fields, significantly improving the depth and usability of data shared. It has also created an opportunity to explore POLAR's capabilities to generate richer insights, informing planning, promoting equity, and strengthening service delivery across programs such as GCfAHPC. Leveraging insights from general practice can help uncover patterns and trends that support evidence-based decision-making and continuous improvement.

PalCare

PalCare is a specialised clinical information system used by community and hospital-based palliative care services. In NWMPHN, providers such as Mercy Health and Melbourne City Mission use PalCare to coordinate patient pathways and monitor palliative care delivery.

The system provides valuable insights into who is being referred to specialist palliative care, the source and timing of those referrals, and key demographic and clinical details such as age, diagnosis, care phase, and, where recorded, cultural, spiritual or linguistic needs. Designed specifically for palliative care, PalCare aligns with national benchmarks such as the Palliative Care Outcomes Collaboration (PCOC).

Palliative care information needs

An aspirational list of palliative care information needs was developed to outline the data required to inform program design and service delivery.

This list was mapped against the information available in POLAR and PalCare to identify whether the data is currently available (see **Table 11**). This mapping highlights several issues affecting the completeness, accuracy, and consistency of palliative care data across primary and specialist systems. Despite these limitations, significant opportunities exist for NWMPHN and general practices to increase engagement with available data, enabling more informed planning, improved equity, and stronger program delivery.

Table 11. Palliative care program information needs mapped to data available in POLAR and PalCare.

Information need	Description	Source		
		POLAR	PalCare	Other
Who is making the referrals to specialist palliative care?	Profession, healthcare setting, and postcode of referrer	x	✓	x
	Number of referrals made by each general practice	P	x	x
Reason for referral to specialist palliative care	What was the primary diagnosis leading to referral?	x	✓	x
	What are the demographics of patients being referred?	P	✓	x
Timeliness of referral to specialist palliative care	What was the length of time from diagnosis to referral?	x	P	PMS
	What stage of their palliative care was the patient referred?	x	✓	
Time spent receiving palliative care	Length of time a patient is receiving palliative care prior to death	x	✓	PMS
Who is providing palliative care?	Which GPs are seeing patients receiving palliative care?	P	x	PMS *(see note 1)* PACOP *(see note 2)*
	Which residential aged care homes have patients receiving palliative care?	x	P	
Uptake of advanced care plans. Which healthcare providers are championing completion?	How many patients per general practice have an advanced care plan?	?	x	Hard copy ACP My Health Record PMS
	What patients in specialist palliative care have an advanced care plan?	x	✓	
	What are the patient demographics of those completing advanced care plans?	P	✓	
General demographics of general practice patients in the region	Are there particular GPs who have a high portion of ageing patients?	✓	x	PMS.
	Are there particular GPs who see a high portion of patients with diagnoses typically seen in palliative care?	✓	x	
	Which GPs are seeing a high portion of patients from diverse populations, such as First Nations, CALD, LGBTIQ+?	P	x	
Key	x not available; P partially available, noting amount of data is not comprehensive; ✓ data available; ? unknown			

Table note: 1: PMS is a type of software used in health care settings such as general practices, medical clinics, and allied health services, to manage administrative and operational functions. Examples of PMS include Best Practice and Medical Director. 2: PACOP data from aged care homes participating in the PACOP program (see **Appendix B**).

Source: Data fields identified through internal NWMPHN staff consultation; they may not capture all relevant factors or perspectives beyond the staff consulted.

Critical gaps in palliative care data

Building on the mapping of information needs to available data, this section summarises insights from the literature and internal consultations regarding current limitations in palliative care data.

The gaps outlined in **Table 12** affect ability to deliver timely, person-centred and compassionate care, underscoring the need for more consistent data capture, improved quality and better integration across primary and specialist care settings.

Table 12. Critical gaps in palliative care data

Key finding	Evidence
1. Primary care provider involvement in palliative and end-of-life care is significant yet largely invisible in national data	Despite their central role in palliative and end-of-life care, generalist palliative care providers including GPs, nurses, and AHPs don't have a dedicated MBS item for palliative care to capture activity including procedures, consultations, or referrals. Consequently, palliative care in general practice is billed under other item codes and cannot be identified in national datasets (AIHW, 2024a) POLAR aggregates de-identified practice management record data from general practices[1] including demographics, diagnoses, prescribing, MBS/PBS usage, and pathology requests. It provides population level insights including ageing and chronic disease patterns, but does not currently capture dedicated palliative care codes or activity.
2. Palliative care data is fragmented across general practice, hospital and community palliative care systems.	Palliative care data is stored in separate systems that use different definitions and reporting standards. Each capture only part of a person's care, making it difficult to form a complete picture. For example, palliative care data sits across disconnected systems (GP, hospital, specialist), each capturing only part of the patient journey. POLAR can't identify palliative activity, hospital data is separate, and PalCare/PCOC are not linked or accessible to PHNs, limiting regional visibility of care. NWMPHN currently does not have access to PalCare data from local providers, limiting timely visibility of specialist palliative care in the region.
3. Current data systems do not enable visibility of where a person is in their palliative care journey, or continuity of care.	Palliative care is non-linear, and people's care needs change over time and across specialist and generalist services. However, systems used in general practice and specialist palliative care are not linked, preventing a joined-up view of patient journeys, care transitions, referral timeliness, or outcomes. POLAR can identify people at risk of hospitalisation, but there is no equivalent mechanism to identify risk of deterioration or end-of-life need, limiting proactive and timely care planning.
4. ACPs exist but are often not visible across care settings, limiting utility and provision of care aligned with an individual's preferences.	PalCare can identify patients with an ACP, but two issues limit visibility and usefulness across the system: • Patients who are not linked with specialist palliative care may not have an ACP, or the discussion may not have occurred in general practice. • ACPs can exist in multiple formats (for instance, electronic or hard copy) and locations (such as PalCare, GP PMS, My Health Record, paper). Quality varies depending on who supported documentation. This means ACPs are not always accessible when decisions need to be enacted. Therefore, even when ACPs exist, they are not consistently recorded or accessible, creating risk that patients' wishes are unknown at important moments.
5. Cultural, linguistic, gender and disability data are inconsistently recorded, limiting insights needed to identify health inequity.	Few datasets capture patient-specific cultural, spiritual, or identity information that influence palliative care needs, preferences, and experiences. This limits insights about individual preferences, and whether palliative care is culturally safe and responsive. While tools like PCOC include clinical measures, they do not routinely capture cultural values, spiritual needs, or care preferences. Cultural, linguistic, gender, disability and LGBTIQ+ indicators are variably collected across primary care, hospital, and specialist systems. This results in people with intersecting identities, such as LGBTIQ+ Aboriginal and Torres Strait Islander peoples or culturally diverse older adults, being "invisible" in data even when accessing care, making equity assessment and responsive planning challenging.
6. Most available palliative care data reflect hospital and	Currently, most available palliative care data comes from hospitals and specialist services. As a result, we have limited visibility of care delivered in general practice, aged care, and people's homes.

specialist palliative care services, with little visibility of care at home, in general practice, or aged care.	For example, non-admitted hospital and community palliative care activities are not routinely captured, leaving major blind spots in understanding where and how people receive end-of-life care (AIHW, 2024a; Apex Consulting, 2018). As one NWMPHN staff member reflected, “We know that people die at home supported by their clinician, but we don’t have the data visibility to show where, how, and who is providing care.”

Barriers to improving data quality

Challenges in data quality, particularly regarding accuracy, completeness and consistency, are not unique to palliative care and reflect broader systemic issues across primary and specialist care. Addressing these requires a focus on structural factors and workflow design rather than individual performance.

Challenges include:

- Lack of standardised coding practices. System limitations and variations in coding lead to inconsistent data capture across practices.
- Incomplete referral entries. Non-mandatory fields are often left blank, with referrers providing only basic patient demographics.
- Limited granularity of referral sources. Broad categories such as ‘hospital’ or ‘GP’ limit opportunities for data linkage and detailed analysis.
- Competing clinical priorities. Time pressures across primary care reduce capacity for data entry and ongoing quality improvement.
- Perceived low priority of quality improvement. The focus on implementing system-wide reforms can limit engagement with data initiatives. However, reforms often aim to strengthen quality improvement capacity, support accessibility, and improve continuity of care, particularly for people with life-limiting conditions. While reforms can present challenges, they also provide opportunities to embed data-driven improvement into routine palliative care practice.

Opportunities to strengthen palliative care data and equity

Improving palliative care in the NWMPHN region requires better access to, integration of, and use of data across primary, specialist, and community services. Existing systems capture different parts of the care journey, but no single system provides a complete view. Integrating these sources can support more coordinated, equitable, and person-centred care.

Strategic opportunities, outlined in **Table 13**, include strengthening data integration and interoperability, improving early identification of patients, embedding diversity indicators, supporting multidisciplinary care coordination, and exploring additional datasets to inform planning.

Table 13. Opportunities to strengthen palliative care data and equity

Opportunities and actions	Alignment to palliative care and related frameworks
Data-sharing with NWMPHN, specialist palliative care providers, primary care and DHDA and Victorian Department of Health funded programs (for example, PACOP, PCOC, PCAS).	Aligns with NWMPHN’s strategic plan priorities on integrated care. Supports Victoria’s end-of-life and palliative care framework and National Palliative Care Strategy goals on data-driven planning.
Use data to guide early identification of patients needing palliative care, through primary care quality improvement initiatives. These might be activities to improve coding in general practice or identification of likely death within 12 months.	Aligns with NWMPHN objectives for primary care improvement, AIHW Measure 5.2 (Inclusive Care), and National Palliative Care Standards for All Health Professionals and Aged Care Services Standard 1 (Comprehensive assessment of needs).

Leverage POLAR data for insights and program design.	Supports NWMPHN digital health priorities and Victorian Data Reform priorities.
Embed diversity indicators (such as ethnicity, language, gender identity) in national minimum datasets, advance work on NMDS and inclusive care measures.	Aligns with National Palliative Care Strategy principles of equity and Victoria’s end-of-life and palliative care framework focus on inclusion.
Explore additional datasets (Victorian Integrated Non-Admitted Health, PCOC, PACOP) to inform planning and improve understanding of palliative care needs.	Supports NWMPHN understanding of palliative care needs and Victorian Integrated Care priorities.

5. Opportunities

5.1 Opportunities for action

5. Opportunities

5.1 Opportunities for action

This PCNA identifies many opportunities to improve outcomes in palliative care across the NWMPHN region. While these may not necessarily be matters that NWMPHN will implement, they provide an essential framework to guide collaboration with stakeholders in planning and implementing the GCfAHPC program.

This section compiles opportunities for action identified throughout the PCNA process. The synthesis enables the identification of actionable insights that NWMPHN or other parties may leverage to inform potential strategies to enhance outcomes in community palliative care.

Across the following tables, opportunities for action are grouped by high-order themes that revealed five priority areas, with the opportunities pertaining to each being rated in terms of feasibility for implementation (see Methodology).

Table 14. Opportunities for action. Priority area of focus 1: Build primary care capability

Priority area of focus 1: Build primary care capability				
Opportunities and actions	**Purpose and expected impact**	**Within remit and scope of GCfAHPC**	**Impact**	**Effort**
Provide general practice teams with patient resources to prompt ACP and palliative care discussions.	Reduce the burden of initiating difficult conversations and improve the timeliness and quality of these discussions.	Y	High	Low
Develop quality improvement initiatives targeting communication in palliative care.	Embed the use of resources and strategies that support effective patient communication, improve workflows, and enhance communication across care settings.	Y	High	High
Promote existing capability-building opportunities and resources, particularly those available in self-directed or flexible formats.	To increase uptake of evidence-based education and resources, enabling primary care team members to build capability in a flexible way, reducing the impact of resource limitations on attendance.	Y	High	Low
Encourage participation in low-resource, low-commitment peer learning and mentoring opportunities, such as communities of practice (for example, University of Queensland's Palliative Care ECHO), the Victorian Palliative Care Advice Service, and the Victorian Virtual Specialist Consults service.	To provide accessible avenues for shared learning and professional support without significant time or financial burden.	Y	High	Low
Develop local capability-building activities where gaps exist in education offerings.	To address unmet educational needs and support local delivery of evidence-based palliative care practices.	Y	High	High
Promote support strategies for primary care staff, such as debriefing tools and self-care resources.	To recognise and mitigate the emotional burden of delivering palliative care, supporting staff wellbeing and sustained high-quality care delivery.	Y	Low	Low
Disseminate information about billing options and care models.	To increase awareness of available billing pathways, helping overcome barriers related to effective MBS use in primary care.	Y	Low	Low
Use data to guide early identification of patients needing palliative care, through primary care quality improvement initiatives. These might be activities to improve coding in general practice or identification of likely death within 12 months.	Aligns with NWMPHN objectives for primary care improvement, AIHW Measure 5.2 (Inclusive Care), and National Palliative Care Standards for All Health Professionals and Aged Care Services Standard 1 (Comprehensive assessment of needs).	Y	High	High

Table 15. Opportunities for action. Priority area of focus 2: Enhance cultural competency

Priority focus area 2: Enhance cultural competency				
Key opportunities and actions	**Purpose and expected impact**	**Within remit and scope of GCfAHPC**	**Impact**	**Effort**
Increase awareness of effective interpreter use in palliative care.	Improve communication with patients with limited English proficiency and ensure informed decisions about interpreter use. Reduce risks when family interpreters are used and enhance interaction quality and patient support.	Y	High	High
Build cultural competency in primary palliative care.	Share culturally safe care education and resources to improve awareness, communication and care for diverse and vulnerable groups.	Y	High	High

Table 16. Opportunities for action. Priority focus area 3: Improve communication, integration and adoption of digital health initiatives

Priority focus area 3: Improve communication, integration and adoption of digital health initiatives				
Key opportunities and actions	**Purpose and expected impact**	**Within remit and scope of GCfAHPC**	**Impact**	**Effort**
Support uptake of e-referrals and digital health initiatives aiding communication between generalist and specialist palliative care.	To streamline communication processes, reducing administrative workload and time demands. Improved e-referral integration ensures relevant fields are auto-filled, enhancing the quality and completeness of referrals to community palliative care services. Improved communication between providers will facilitate continuity of care, prompt access to key information, and clear roles and responsibilities for all practitioners involved in a patient's care.	Y	High	High
Support increased use of My Health Record for document sharing – for example, uploads of ACPs and patient summaries.	To improve system integration and interoperability across general practice software, PalCare, and My Health Record, ensuring timely access to key documents across care settings. A PalCare patient summary function is expected in 2026.	Y	High	High
Enhance communication between care providers, including shared patient information, to enable multidisciplinary care coordination.	To improve collaboration between primary and community palliative care services, ensuring seamless, patient-centred care delivery.	Y	High	High

Table 17. Opportunities for action - Priority focus area 4: Increase community and primary care awareness

Priority focus area 4: Increase community and primary care awareness				
Key opportunities and actions	**Purpose and expected impact**	**Within remit and scope of GCfAHPC**	**Impact**	**Effort**
Deliver awareness-raising campaigns for community and primary care teams.	Improve understanding of palliative care and ACP among health professionals and the community, supporting timely initiation of conversations.	Y	High	Low
Promote availability of services that support primary care professionals, families, and carers who require further information.	Increase awareness and use of specialist advice and secondary consult services.	Y	High	Low
Share case studies of positive patient and family experiences.	To demonstrate the real-world impact of timely, quality care and provide relatable examples for practitioners, reinforcing relevance to their work.	Y	Low	Low

Table 18. Opportunities for action. Priority focus area 5: Use local data to monitor, evaluate and improve primary care programs

Priority focus area 5: Use local data to monitor, evaluate and improve primary care programs				
Key opportunities and actions	**Purpose and expected impact**	**Within remit and scope of GCfAHPC**	**Impact**	**Effort**
Data-sharing with NWMPHN, specialist palliative care providers, primary care, DHDA and Victorian Department of Health funded programs (for example, PACOP, PCOC, PCAS).	Aligns with NWMPHN Strategic Plan priorities on integrated care. Supports Victoria's end-of-life and palliative care framework and National Palliative Care Strategy goals on data-driven planning.	Y	High	High
Leverage POLAR data for insights and program design.	Supports NWMPHN digital health priorities and Victorian data reform priorities.	Y	Low	Low
Embed diversity indicators (such as ethnicity, language, gender identity) in national minimum datasets, advance work on NMDS and inclusive care measures.	Aligns with National Palliative Care Strategy principles of equity and Victoria's end-of-life and palliative care framework focus on inclusion.	N	N/A	N/A
Explore additional datasets (Victorian Integrated Non-Admitted Health, PCOC, PACOP) to inform planning and improve understanding of palliative care needs.	Supports NWMPHN understanding of palliative care needs and Victorian Integrated Care priorities.	Y	High	High

6. References

6. References

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Appendices

Appendices

Appendix A: List of palliative care services in the NWMPHN region

These services provide specialist and generalist palliative care in the NWMPHN region (as at November 2025)

Service	Service details
Community palliative care services	
Melbourne City Mission Palliative Care	Servicing Darebin, Hume, Merri-bek and Yarra LGAs
Mercy Palliative Care (Mercy Health)	Servicing Brimbank, Hobsons Bay, Maribyrnong, Melbourne, Melton, Moonee Valley and Wyndham LGAs
Bacchus Marsh Community Palliative Care Service (Western Health)	Servicing Moorabool LGA in the NWMPHN region
Kyneton Health Palliative Care (Central Highlands Rural Health)	Servicing Macedon Ranges LGA in the NWMPHN region
Public hospital palliative care services	
Parkville Integrated Palliative Care Service (Royal Melbourne Hospital, Peter MacCallum Cancer Centre, Royal Women's Hospital)	• Inpatient palliative care unit (Royal Melbourne Hospital) • Palliative care consultancy service • Outpatient palliative care clinic • Residential in-reach service (Royal Melbourne Hospital)
Mercy Health	• Inpatient palliative care unit (Werribee Mercy Hospital) • Outpatient palliative care clinic • Residential in-reach service
Western Health	• Inpatient palliative care unit (Sunshine Hospital) • Palliative care consultancy service • Outpatient palliative care clinic • Residential in-reach service
Central Highlands Rural Health (Kyneton Health)	• Inpatient palliative care unit (Kyneton Health) • Outpatient palliative care clinic (visiting specialist)
Austin Health	• Inpatient palliative care unit (Olivia Newton-John Cancer Wellness & Research Centre) • Palliative care consultancy service • Outpatient palliative care clinic • Residential in-reach service
Northern Health	• Inpatient palliative care unit (Northern Hospital Epping) • Palliative care consultancy service • Outpatient palliative care clinic • Residential in-reach service
St Vincent's Hospital Melbourne	• Inpatient palliative care unit (St Vincent's Hospital; Caritas Christi Hospice) • Palliative care consultancy service • Outpatient palliative care clinic

Service	Service details
	- Residential in-reach service
Victorian Paediatric Palliative Care Program (Royal Children's Hospital, Monash Health, Very Special Kids)	The Victorian Paediatric Palliative Care Program provides specialist paediatric palliative care advice to health professionals caring for children with a life-threatening condition and their families. The program comprises specialist doctors, social workers, occupational therapists and nurses who work closely with each of the member organisations to identify children, coordinate care and provide appropriate advice regarding various aspects of patient management. The team does not provide direct patient care.
Telehealth and support services	
Victorian Virtual Specialist Consults (VVSC)	Statewide service providing GPs, nurses and allied health professionals specialist advice to facilitate ongoing patient management including palliative care and advanced care planning through case conferences or co-consults.
Victorian Palliative Care Advice Service (PCAS)	Statewide service providing specialist palliative care information and advice to all Victorians.
Victorian Virtual Emergency Department (VVED)	Statewide public health service for non-life-threatening emergencies, providing access to emergency doctors and nurses to all Victorians, including on-demand co-consults for healthcare providers and aged care homes.
Statewide Voluntary Assisted Dying (VAD) Care Navigator Service	Statewide service providing information and support to people seeking to access VAD, and their families, carers and support people. If necessary, it can connect people with medical practitioners who have completed VAD training. The service also provides information, support and training to health practitioners, health and aged care services, and palliative care services.
Other primary care services	
General practices	There are 546 general practices in the NWMPHN catchment
Aboriginal health services	- Aboriginal Community Elders Services Incorporated - The Victorian Aboriginal Health Service Co-operative Limited - Victorian Aboriginal Community Controlled Health Organisation
Community health services	- Access Community Health (Yarra) - cohealth (Maribyrnong, Moonee Valley, Yarra) - DPV Health (Hume, Melton) - Holstep Health (Merri-bek) - IPC Health (Brimbank, Hobsons Bay, Wyndham) - Macedon Ranges Health (Macedon Ranges) - North Richmond Community Health (Yarra) - Sunbury and Cobaw Community Health (Hume) - Western Health (Melton, Moorabool) - Your Community Health (Darebin)

Service	Service details
Residential Aged Care Homes	There are 128 RACHs in the NWMPHN catchment
Pharmacies	There are 375 pharmacies in the NWMPHN catchment, 110 of which have committed to stocking palliative care core medicines and are listed on the associated pharmacy locator map: Palliative care core medicines list and pharmacy stockists
Allied health services	There are 1437 allied health services in the NWMPHN catchment

Appendix B: Palliative care programs in the NWMPHN region

These programs support palliative care delivery and improvement in the NWMPHN region (as at November 2025)

Peak bodies and support organisations

- Palliative Care Australia
- Palliative Care Victoria
- North and West Metropolitan Region Palliative Care Consortium

Australian Department of Health, Disability and Ageing palliative care programs and initiatives

- Advance Care Planning Australia
- CarerHelp
- CareSearch – Palliative Care Knowledge Network
- Caring@Home – Symptom management for palliative patients
- Comprehensive Palliative Care in Aged Care measure
- End of Life Direction for Aged Care (ELDAC)
- End of Life Essentials – education for acute hospitals
- End of Life Law for Clinicians (ELLC)
- Greater Choice for At Home Palliative Care Program
- Gwandalan National Palliative Care Project
- Improving palliative care services for people with an intellectual disability
- Indigenous Program of Experience in the Palliative Approach (IPEPA)
- LGBTIQ+ Health Australia
- palliAGED – palliative care aged care evidence
- Palliative Aged Care Outcomes Program (PACOP)
- Palliative Care Australia
- Palliative care curriculum for undergraduates (PCC4U)
- Palliative care in Australian prisons
- Palliative Care Outcomes Collaboration (PCOC)
- Palliative Care Pharmacist Foundation Training Program
- Palliative Care Project Echo
- Palliative Care Service Navigation Pilot
- Program of Experience in the Palliative Approach (PEPA)
- Quality of Care Collaborative – Australia (QuoCCA)
- Shaping the Future of Paediatric Palliative Care
- Talking End of Life – with people with intellectual disability (TEL)
- The Advance Project
- The National Palliative Care Coordination Program

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- Palliative Care Program
- Advance care planning
- Voluntary Assisted Dying
- Victoria's end-of-life and palliative care framework

Appendix C: Detailed list of data sources and limitations

Each data source has its limitations, but these are reduced when triangulated with other sources.

Dataset | data source	What the data tells us about palliative care	Strengths	Limitations
ABS Death Registrations / National Death Index (NDI)	Registered deaths (cause, age, place).	✓ Place of death analysis. ✓ Robust denominators	X No palliative care flag (lacks linkage) and release is lagged. X Indigenous identification quality varies by jurisdiction; limited visibility of LGBTIQ+, disability, homelessness or incarceration status.
ABS Census (2021)	The Australian census of provides a cross-sectional view of the country and tells the story of how we are changing.	✓ Provides the most comprehensive data on the Australian population.	X Only conducted every five years. X Suppression and aggregation methods are used to protect data privacy; however, data is not always disaggregated to a fine enough level. X Only disseminated in English, underrepresenting culturally and linguistically diverse populations including migrants and people seeking asylum. X Doesn't capture diverse genders or sexual identities.
APC (Admitted Patient Care) – National Hospital Morbidity Database (NHMD)	All inpatient episodes: palliative identified via care-type and/or ICD-10-AM Z51.5.	✓ Provides good view of inpatient activity (trends, age, diagnosis and length of stay analysis) ✓ PHN-level reporting available (via AIHW dashboard)	X Coding practices inconsistent (e.g., care type and diagnosis). X Private hospital service configuration may affect capture. X Patient equity variables limited or inconsistent (e.g. gender recorded as binary; Aboriginal and Torres Strait Islander identification quality varies)
Death literacy survey (n=32)	Primary care (GP/ nurses) knowledge, confidence and support needs about serious illness, dying and bereavement.	✓ Lived experience insight ✓ PHN-level / local level insights.	X Small sample is not representative and limited comparability beyond local context. X Selection / response bias.

Dataset | data source	What the data tells us about palliative care	Key strength/s	Key limitation/s
Internal (targeted) interviews (n = 5)		✓ Enhanced data richness and triangulation were achieved by combining qualitative consultation insights with quantitative data. ✓ Targeted interviews with internal SMEs (e.g., palliative care program teams, POLAR / PalCare system users) identified opportunities for quality improvement.	X Small sample X Selection / response bias (organisational perspective may bia findings)
Semi-structured interviews (primary care professionals) (n=14)		✓ PHN-level / local level insights. ✓ Enhanced data richness and triangulation were achieved by combining qualitative consultation insights with quantitative data.	X Small sample
Medicare Benefits Schedule (MBS) items/claims	Medicare billed services (GP, nurse and AHP activity), palliative medicine specialist activity.	✓ National coverage. ✓ Specific palliative care items across hospital-based and community-based settings. ✓ PHN-level reporting available	X Generalist palliative care activity largely invisible (GPs bill under general items). X Public hospital clinics often don't bill MBS. Therefore, billing doesn't equate to total care delivered.
Palliative Care Outcomes Collaboration (PCOC)	Outcomes from participating in specialist services (phase of care, Australia-modified Karnofsky Performance Status (AKPS), symptom assessment scale (SAS) and timeliness measures; used for benchmarking and QI.	✓ Good local community-basec service-level detail including clinical severity and outcomes – uses standardised measures to enable benchmarking. ✓ Useful for service QI.	X Voluntary participation nationally. X Coverage varies by service/region. X Data accessibility – currently do not have access (requires data sharing agreement).
Pharmaceutical Benefits Scheme (PBS)	Subsidised community prescriptions (including palliative-listed medicines).	✓ National coverage. ✓ Captures community/ PHN level prescribing trends (utility, medication type, demographics)	X Prescriptions are not equivalent to number of patients X Some medications prescribed in hospital, dispensed in community X Limited clinical detail

Dataset | data source	What the data tells us about palliative care	Key strength/s	Key limitation/s
Primary health care data / POLAR		✓ Captures 80% of GP clinics in NWMPHN. Good representation.	X No palliative care specific flag. X Equity indicators often incomplete or binary (gender), with gaps for LGBTIQ+, disability, refugees, homelessness and incarceration
Workforce data: registrations and surveys (AIHW, HeaDSUPP)	Total FTE/ number per 10,000 population,	✓ National totals and time series with some geographic breakdowns (state/LGA) • Identifies broad workforce availability (supply) trends.	**No palliative-care specialty flag** for most allied health, nursing, social work, pastoral care and therefore can't quantify the palliative workforce. **PHN-level data rarely available** Role/scope (generalist vs specialist) not captured; data often lagged.

Equity data constraints

- **Gender diversity:** Most datasets record sex or gender as a strict male–female binary, limiting visibility of non-binary, trans or intersex people.
- **Aboriginal and Torres Strait Islander identification** – incomplete or inaccurate identification is common in administrative and clinical systems (for example, variations in collection practices and data quality).
- **Priority populations with major data gaps** – LGBTIQ+ communities, people with disability, asylum-seekers and refugees, people experiencing homelessness, and people in prisons. Intersectionality across these attributes is largely absent, constraining equity analyses at PHN level.

Appendix D: Internal and external consultations

The groups consulted, recruitment processes, and analyses are detailed here.

	Provider consultations	Internal consultations	Death Literacy Index (DLI-9 Survey)
Population	External primary health providers	Internal NWMPHN staff	External primary health providers
Inclusion criteria	Primary care provider providing palliative care in the NWMPHN region	Employed at NWMPHN at the time of analysis	Primary care provider providing palliative care in the NWMPHN region
Data collection method	6 in-depth semi-structured interviews	2 in-depth semi-structured interviews	Online Death Literacy Index (DLI-9) Survey
Number of participants	N = 14	N = 5	N = 32
Analysis	Inductive qualitative analysis: Transcripts from interviews were analysed and key words and phrases were coded. Codes were used to derive at set of sub-themes which were then grouped into high-order themes. This resulted in a qualitative framework (see **E**). Quotes were extracted according to their original code.	Inductive qualitative analysis: Transcripts from interviews were analysed to develop thematic summary insights. No qualitative coding was undertaken.	Quantitative scoring as per DLI-9. See Progressing the Death Literacy Index: the development of a revised version (DLI-R) and a short format (DLI-9) - Kerrie Noonan, Andrea Grindrod, Sumina Shrestha, Sora Lee, Rosemary Leonard, Therese Johansson, 2024
Recruitment	EOIs for the consultations were promoted through the following channels to reach the intended audience of local primary care professionals: - Newsletters: Network news, GP newsletter, GP CPD newsletter - 2024-25 GCfAHPC project participants - Basecamp forums: practice nurses and practice managers - LinkedIn posts in September	NWMPHN staff from IPDS and HIS teams that are involved with the GCfAHPC initiative and supported the transition to POLAR.	The survey was promoted through the following channels to reach the intended audience of local primary care professionals: - PHCI and Aged Care Teams - Older Adults EAG, GP EAG - Primary Care Voices mailing list - Newsletters: Network news, GP newsletter, GP CPD newsletter - 2024-25 GCfAHPC project participants - Basecamp forums: practice nurses and practice managers - LinkedIn paid campaign throughout October - Project stakeholders: PalCal consortium and PalCare ECHO project - Consultation interview participants, with request to share with colleagues

Appendix E: External consultations: Qualitative coding framework

Themes, sub-themes and ideas that emerged from analysis of external consultation data.

Theme	Sub-theme	Main ideas
Care coordination and delivery	**Providing emotional, social and psychological support to patients and families**	GPs described the importance of attending to patients' psychological, emotional, and social needs by creating spaces where individuals feel safe to express themselves. This includes offering opportunities for patients to ventilate their feelings, share concerns, and articulate expectations without fear of judgment. Practitioners emphasised the value of simply being there to provide holistic support in an environment that fosters trust and enables meaningful communication. These interactions were seen as central to holistic care, particularly in contexts where emotional distress or uncertainty may be prominent.
	Coordinating and delivering holistic, culturally responsive care	GPs described their central role in coordinating care across a network of practitioners, including nurses, family members, carers, and specialist palliative care teams. This coordination was seen as essential to effective symptom management, particularly around prescribing for pain and comfort. Nurses were recognised as key partners in delivering hands-on care, especially in managing pain and providing comfort, often acting as the frontline in implementing treatment plans. All participants also emphasised the importance of being responsive to the diverse cultural, linguistic, and belief contexts of patients and families, and how these shaped clinical decisions and communication. Building strong, collaborative relationships with palliative care teams enabled GPs and nurses to ensure that every necessary support was in place, with nurses playing a vital role in maintaining continuity and quality of care.
	Establishing shared care pathways and communication systems for continuity	All participants emphasised the importance of maintaining open communication channels with a range of providers, including specialists and palliative care teams, to ensure coordinated and consistent care. They identified the need for a universally adopted tool or system—shared across general practice, hospitals, and community health services—that could standardise communication, support continuity, and reduce the burden on patients, such as having to repeatedly recount their medical history. Such systems were universally seen as critical to improving care integration and ensuring that all parties are aligned in their understanding of the patient's needs and preferences.
	Navigating complex, culturally sensitive and time-intensive conversations	GPs described the challenges of initiating conversations about illness progression, death, dying, and ACP, noting that these discussions are often delayed or overshadowed by immediate clinical concerns such as symptom management. Practitioners emphasised that a strong, trusting relationship with patients and families is essential for navigating these sensitive topics. Cultural and belief systems significantly shape how these conversations unfold—affecting preferences around medication, disclosure of prognostic information, and decision-making. Even when GPs feel equipped to have these discussions, limited time and emotional complexity, including patients' and families' hopefulness or reluctance, can hinder meaningful engagement. ACP and palliative care meetings were described as particularly time-consuming, requiring space and sensitivity that current systems often fail to support.

	Funding and structural barriers constrain holistic palliative care	All participants described significant structural and funding challenges that constrain their ability to deliver holistic and coordinated palliative care. Inadequate "fee-for-service" funding models within Medicare were seen as misaligned with the time-intensive nature of palliative care, especially for patients with chronic and complex needs. Participants highlighted the lack of support for staffing, multidisciplinary collaboration and extended consultations, noting that much of this work falls on general practices without dedicated resources. The absence of funding for team-based care, secondary consultations and nurse-led initiatives was perceived as a major barrier to quality holistic care. Time emerged as a critical but unfunded resource, with GPs expressing frustration that meaningful engagement with patients is often rushed or deprioritised due to financial constraints. Some participants drew direct comparisons from their experience of working within international systems that better supported GPs to deliver holistic palliative care, which underscored the limitations of the Australian model and its impact on continuity, equity and patient experience.

Theme	Sub-theme	Main ideas
Timely and continuous care	**Reactive and late engagement with advance care planning after difficult news**	GPs described how patients often return to them after receiving difficult diagnostic or prognostic news from specialists, seeking support and a clearer understanding of their situation. These moments frequently become informal entry points for ACP, though practitioners noted that such conversations often occur late—sometimes when patients are no longer able to make informed decisions. ACP is commonly raised in the context of legal or financial planning, such as when families begin discussing wills or medical powers of attorney. While these processes can provide practical openings for end-of-life discussions, GPs also observed a degree of hesitation among patients and families in accepting palliative care or referrals, which can further delay timely planning and support.
	Building strong relationships and communication to support patient-centred care	GPs highlighted the central role of communication and relationships in delivering patient-centred care. Knowing who to contact and when was seen as critical to providing timely support. Face-to-face interactions were particularly valued, especially in culturally and linguistically diverse contexts where interpreters or community liaisons could help bridge understanding. Family members were recognised as key partners in care, often able to interpret non-verbal cues and support communication. Practitioners emphasised that building strong relationships with patients and their families enables more responsive, respectful, and personalised care.
	Ineffective information sharing and coordination across care settings	GPs described significant challenges in communicating and coordinating with hospitals, palliative care teams, and aged care homes. Information sharing was often inefficient, with practitioners spending excessive time on the phone and receiving incomplete or delayed updates—particularly from public systems and residential aged care homes. The lack of standardised protocols and shared care pathways contributed to confusion about roles and responsibilities, limiting GPs' ability to provide more than emotional and social support. These gaps in documentation and communication were seen to undermine continuity of care and may contribute to patient hesitation in engaging with palliative services. Practitioners emphasised the need for integrated systems and clearer handover processes to support collaborative, patient-centred care.
	Fragmented referral timing	GPs described challenges in the referral process to palliative care teams, noting that while they are often the first to recognise the need for palliative

	and continuity across care settings	support, patients may face delays due to service criteria or capacity constraints. Once referred, the transition is frequently fragmented as patients may not return to their GP, or there may be a significant gap before the palliative care team assumes responsibility. This leaves GPs managing acutely unwell patients without adequate support, undermining continuity and coordination. The lack of a shared care model or structured handover process contributes to a sense of disconnection between primary, specialist and palliative care services.

Theme	Sub-theme	Main ideas
Workforce capability	**Limited formal training and preparedness in palliative care**	GPs and nurses reported a lack of formal training and certification in palliative care, contributing to variable levels of confidence and preparedness across practices. Many practitioners felt under-equipped to manage complex aspects of care, such as prescribing opioids or initiating ACP conversations—particularly when dealing with non-cancer diagnoses or uncertain prognoses. Nurses in general practice settings were seen to have less experience compared to those in specialist palliative roles, and support structures for skill development were often lacking. GPs also noted limited awareness of available resources and described relying on fragmented communication, such as receiving faxed prescription requests, which further highlighted systemic gaps in training and coordination.
	Building capability through training, peer support and practice resources	GPs and nurses emphasised the importance of ongoing training, peer support, and practical resources in developing confidence and competence in palliative care. Real case discussions, debriefing, and collaborative learning were seen as more effective than passive materials alone. Peer networks—such as informal groups or digital platforms—enabled practitioners to seek advice and share experiences, particularly when managing complex cases. Practice staff, especially nurses, were recognised as essential partners in care planning and patient engagement, including facilitating ACP conversations. Access to structured resources, such as ACP information packs, and clear organisational expectations around documentation and data capture further supported capability building across the team.
	Emotional and attitudinal barriers impacting palliative care delivery	GPs described a range of emotional and attitudinal barriers that complicate the delivery of palliative care. Some practitioners reported stepping back after referring patients to specialist teams, unsure of their ongoing role or reluctant to interfere, while others expressed feelings of inadequacy or regret following a patient's death. Patients and families often hesitated to engage with palliative care, influenced by misconceptions that it signals imminent death and by limited awareness of ACP. These challenges were compounded by societal narratives that frame death and ageing as failure, discouraging open dialogue. Additionally, some GPs expressed discomfort or lack of confidence in prescribing opioids, reflecting broader attitudinal barriers that can hinder effective symptom management and care planning.
	Facilitating communication and education on palliative care	GPs described their central role in educating patients, families, and carers about palliative care and ACP, often stepping in where specialists focus solely on disease-specific issues. This educational role was shared across the practice team—including nurses, registrars, and allied health staff—who collectively worked to provide information, resources, and caregiver support. Practitioners emphasised the importance of empathetic communication, creating space to express concerns and answer questions. Patients frequently returned to their GP seeking clarity and understanding, highlighting the need

		for ongoing, relationship-based engagement to support informed decision-making and acceptance of palliative care.
	System-level initiatives to formalise care and raise palliative care awareness	Participants highlighted the value of system-level initiatives in improving both professional practice and public understanding of palliative care. Media coverage and public-facing education were seen as important for raising awareness of available supports and normalising conversations about end-of-life care. Within the health system, practitioners emphasised the need for formalised and standardised templates to clarify roles, responsibilities, and communication processes across services. Embedding structured tools into clinical software—such as conversation guides for ACP—was viewed as a practical way to support GPs and nurses in navigating complex discussions and ensuring consistent, high-quality care.

Appendix F: External consultation provider overview

The purpose of external consultations was to:

- Collect local knowledge and perspectives about primary palliative care.
- Gain an understanding of the key challenges faced by general practice when it comes to delivering palliative care in our region.
- Gather insights about enabling factors and practical solutions that could support general practices in the delivery of quality palliative care and advance care planning.

The protocol was based literature review findings for research question two on palliative care in primary care settings, including barriers, enablers, and potential strategies.

This supported the design of practical, context-sensitive interventions and generated activity ideas for the primary care consultations:

- Structured strategy ranking (quantitative)
- Open-ended questions (qualitative)
- Scenario-based discussion (creative)
- Death Literacy Index questionnaire (DLI-9) (quantitative) – this was implemented as an online survey, separate to the interviews.

Protocol version 1

This version was used for the first semi-structured interview.

Part 1: An open-ended question segment asked participants:

- What do you see as your role in palliative care?
- What barriers do you encounter most often in delivering palliative care?
- What would make it easier for you to engage in advance care planning?
- How do cultural or community factors influence your approach to palliative care?
- Which strategies, if any, have worked well in your practice to support effective advance care planning or palliative care?

Part 2: A strategy matrix activity presented participants with ten evidence-based strategies to support better integration of palliative care and advanced care planning in primary care. (Refer to strategy list in table below.) Participants were asked to rank effectiveness and feasibility, followed by discussion questions.

- Rank effectiveness – How effective do you think each strategy would be in improving palliative care/ACP in your context? (Rank 1-10)
- Rate feasibility – On a scale of 1-5, how feasible is each strategy in your setting? (1=not at all feasible, 5=highly feasible) Feasibility may include time, staff, resources, financial costs, etc.
- Discussion based on activity results – Any comments on barriers, enablers, or context about why strategies may or may not be effective/feasible.
- Is there anything missing from this list that you think would be important?
- Which one or two strategies do you believe should be prioritised first in your setting?

Protocol version 2

The initial protocol was adjusted slightly based on the facilitators' experience of conducting the first consultation. The following amendments were made:

- Part 1: In the open-ended questions segment, extra prompts were added to gather deeper insights if communication issues were raised. ‘Communication/care coordination’ was added to the list of Palliative care role prompts (Q1), and a new follow-up question prompt, ‘Explore communication challenges (with patients/families or services),’ was added to Q2-4.
- Part 2: In the strategy matrix, the description of ‘Community campaigns’ was amended to ‘Normalising ACP and palliative care conversations by sharing campaign information’ to better reflect the role the participants would play in such a strategy.
- A follow-up question prompt was added to Q3 to ensure discussions captured ideas and opportunities, not only barriers: ‘If discussion is focused on barriers/reasons for unfeasibility – prompt to consider solutions, identification of opportunities or strategies.’

Protocol version 3

The protocol was adjusted after interview 5 as project team determined that the matrix activity was unlikely to generate significantly different results or additional insights with the remaining interviewees.

The decision was made to replace the matrix activity with a case study discussion as an alternative channel to identify clinical approaches, tools, resources and strategies used by participants in the management of a palliative patient.

The following amendments were made:

- Part 1: Unchanged from Version 2
- Part 2: The strategy matrix activity replaced with case discussion where two patient scenarios were presented, and participants were invited to respond to one or both of the cases. The strategy matrix was maintained in case time permitted but limited it to the completion of the ranking and feasibility activity (Q1-2) for quantitative purposes, removing Q3-5 from the segment. Both interviews 6 and 7 were able to complete the matrix activity with brief follow up comments.

Scenario 1: 84-year-old woman with end-stage COPD, lives alone, given prognosis of <12 months by respiratory team

Scenario 2: 65-year-old man with terminal lung cancer, speaks Arabic and limited English, is a devout Muslim, referred to palliative care by his oncologist

Further information was provided to participants about the patients’ backgrounds, medical histories and presenting situations. Participants were then asked the following questions:

- Would anyone like to share how they might approach one of these cases?
- What if we think about further along [patient name’s] journey – if we’re further into the disease trajectory and things have escalated, is there anything you would change about how you approach their care?

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