Palliative Care and End-of-life Care Needs Assessment

December 2025

Healthy North Coast acknowledges the Traditional Custodians of the lands across our region – the Birpai, Bundjalung, Dunghutti, Githabul, Gumbaynggirr and Yaegl Nations – and pays our respects to Elders past, present and on their journey. We recognise these lands were never ceded and acknowledge the continuation of culture and connection to the land, sky and sea. We acknowledge Aboriginal Peoples as the Land's first peoples and honour the rich diversity of the oldest living cultures.

Please note, in this document, the term 'Aboriginal peoples' is used to refer inclusively to individuals who identify as either Aboriginal, Torres Strait Islander, or both Aboriginal and Torres Strait Islander.

Contents

Figures

Abbreviations

Term	Description
ABS	Australian Bureau of Statistics
ACCHO	Aboriginal Community Controlled Health Organisation
ACD	Advance Care Directive
ACP	Advance Care Planning
AIHW	Australian Institute of Health and Welfare
AMS	Aboriginal Medical Service
DVA	Department of Veteran Affairs
GCfAHPC	Greater Choice for Palliative Care at Home
GP	General Practitioner
HNC	Healthy North Coast
IMoS	Integrated Model of support for Residential Aged Care
LGA	Local Government Area
LHD	Local Health District
MNC	Mid North Coast
NDIS	National Disability Insurance Scheme
NNSW	Northern New South Wales
NPCC	National Palliative Care Coordination
PSA	Pharmaceutical Society of Australia
RACGP	The Royal Australian College of General Practitioners
RACH	Residential Aged Care Home

1. Executive summary

The demand for palliative and end-of-life care on the North Coast is increasing, driven by an ageing population and high prevalence of chronic conditions. The Greater Choice for At Home Palliative Care (GCfAHPC) program – an Australian Government Initative, is funded by the Australian Government to enable Primary Health Networks (PHNs) to improve access to safe, high-quality palliative care at home for people with a life limiting illness.

This needs assessment examines the current and emerging palliative and end-of-life care needs on the North Coast. The findings will guide Healthy North Coast (HNC) in the next stage of the GCfAHPC cycle (2025-2029) with service planning, commissioning, workforce development, and community engagement. The goal is to strengthen awareness, access, and quality of palliative care services across the North Coast region.

The key findings include:

- Advance care planning (ACP) engagement and completion rates remain low on the North Coast. There is considerable variability in the documentation used, storage systems, and accessibility of ACP and advance care directive (ACD) documents across care settings.
- The demographic and chronic disease health trends make the North Coast one of the most palliative-care-intensive regions in NSW.
- Workforce distribution, capacity, and navigation are considerable challenges. Access to generalist and specialist services is uneven, clinician burnout is high, and confidence in initiating ACP can be improved.
- General practice plays a central role in the provision of palliative and end-of-life care but is often constrained by competing demands and limited resourcing. There is a need for continued education in primary care regarding the scope and processes related to generalist palliative care.
- There is limited awareness of palliative care in the community. Greater recognition is needed for palliative care to be recognised as holistic support for people living with a range of life-limiting chronic conditions and for its broader focus on improving quality of life throughout illness.
- Carers are critical to sustaining home-based care and preventing avoidable hospitalisations. Compassionate Communities Australia and death literacy initiatives strengthen informal supports and complement formal services.
- Culturally safe, inclusive, and person-centred care is critical to meeting the needs of diverse and vulnerable populations across our region and ensuring the workforce are competent to deliver this care.
- Effective care coordination and integration of services is critical. Streamlined pathways and clear communication between healthcare providers, patients and families are essential to ensure continuity of care and improve the patient and family experience across a system that is fragmented and difficult to navigate.
- National programs present opportunities to benchmark performance, embed evidence-based practice, and drive continuous quality improvement.
- Technology and data (virtual care, My Health Record, HealthPathways) support the access, care coordination, and documentation of patient preferences. Challenges

include record maintenance, poor user-experience of platforms, and lack of appropriate Medicare billing codes to facilitate clinician involvement.

2. Key concepts

Palliative care

Palliative care is a person- and family-centred approach to care for people of any age living with a life-limiting illness and their families. It identifies and treats physical, emotional, spiritual, and psychosocial needs associated with life-limiting conditions, while providing support to both patients and their family and carers. Palliative care can be provided from the time of diagnosis and delivered alongside other life-prolonging or disease-modifying treatments. The aim is neither to hasten nor postpone death, but to focus on living as well as possible for as long as possible. Palliative care is delivered by multidisciplinary teams (doctors, nurses, allied health professionals, social workers, trained volunteers) across various settings (homes, hospitals, hospices, residential aged care homes, outpatient clinics). The care extends beyond symptom management to include medication management, nutritional support, equipment provision, counselling, respite care referrals, and ongoing bereavement support for families after death (Palliative Care Australia, 2024).

End-of-life care

End-of-life care includes physical, spiritual, and psychosocial assessment, care and treatment delivered by health professionals and ancillary staff. It includes support for families and carers, and care for the patient's body after their death. People are considered to be approaching the end-of-life when they are likely to die within the next 12 months (AIHW, 2016). End-of-life care and palliative care are often used interchangeably and they refer to services targeted to different stages of people's life-limiting illnesses.

Palliative care can begin as soon as a person is diagnosed with a life-limiting condition and can continue for many years. End-of-life care represents a specific timeframe, usually the last 12 months of life, but may be only the last few days of life.

Advance care planning

Advance care planning (ACP) is a voluntary process where individuals make plans for their future health care. It enables people to make decisions about the health care they would or would not like to receive if they were to become seriously ill and unable to communicate their preference for making decisions (NSW Health, 2025; Advance Care Planning Australia, 2025).

Advance care directive

An advance care directive (ACD) guides medical decisions when a person no longer has decision-making capacity. In cases where the ACD specifies a directive refusing medical intervention, a health practitioner cannot provide treatment, and this cannot be overridden by the enduring guardian (NSW Health, 2025).

Enduring guardianship

An enduring guardianship is a document authorising someone to make lifestyle, health or medical decisions for another individual. An enduring guardian can influence or decide where someone lives, and the health, service and medical treatments they receive (NSW Government, 2025).

3. Background

The Greater Choice for At Home Palliative Care (GCfAHPC) program provides funding for palliative care coordination through Primary Health Networks (PHNs). The program aims to improve palliative care coordination and integration to support people who have a life-limiting illness by improving choice and quality of care and support in the home. Healthy North Coast (HNC) leads the program for the North Coast region, working in partnership with the 2 local health districts (LHDs) (Northern NSW LHD and Mid North Coast LHD), general practices, residential aged care homes (RACHs), and community organisations. The GCfAHPC program objectives are to:

- improve access to palliative care at home and support end-of-life care systems and services in primary health care and community care
- enable the right care at the right time and in the right place, to reduce unnecessary hospitalisations
- generate and use data to support continuous improvement of services across sectors
- use available technology to support flexible and responsive palliative care at home, including after-hours.

Between January 2022 and June 2025 HNC developed and implemented innovative projects in end-of-life care planning and palliative care, including:

- delivery of initiatives to improve community awareness and understanding of palliative and end-of-life care and the importance of end-of-life planning
- clinician education and training to strengthen capability in a palliative approach and build knowledge on advanced care planning (ACP) and end-of-life care law
- support quality improvement for primary care and aged care providers to embed ACP, coordinated care and an early intervention approach to palliative care, including the promotion of anticipatory planning
- ongoing review of regional palliative care pathways to enhance integration and ensure people receive the right care in the right setting.

To guide the initial funding cycle of GCfAHPC, a comprehensive Palliative and End-of-Life Care needs assessment was completed in 2023. The program has been extended for a further 4 years from 1 July 2025 to 30 June 2029. This new needs assessment builds upon that initial work, offering additional context and updated insights into areas that are relevant to current and emerging local community needs. It examines quantitative and qualitative data from programs and initiatives delivered during the first program period, triangulated with additional data sources, to provide a detailed picture of community needs and priorities.

While the Australian Government Department of Health, Disability and Ageing 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.

4. Needs assessment approach and process

To identify local needs, HNC used an approach that combines qualitative insights with quantitative data analysis. This enabled a robust understanding of both lived experience and service system dynamics and the interplay between these.

A variety of primary and secondary quantitative data sources were used for this needs assessment, including:

- Australian Bureau of Statistics (ABS)
- Australian Institute of Health and Welfare (AIHW)
- NSW Planning
- HealthStats NSW
- NSW Local Health District data
- General practice data (practice aggregation tool for the clinical audit tool, PATCAT)
- commissioned services.

The needs assessment is informed by 2 surveys: the Better Health Community Survey (n=3,328) undertaken as part of the 2025-2028 core health needs assessment and a dedicated palliative care clinician survey (n=17) conducted in June 2025.

Additional qualitative data was collected through community and provider engagement activities, including education events. Semi-structured interviews were undertaken between July and October 2025 with:

- 2 general practitioners
- 2 dementia specialists
- a social worker
- a nurse educator, specialist palliative care from a LHD
- one palliative care peak body (Palliative Care NSW)
- 2 palliative care leads, from Northern NSW LHD and Mid North Coast LHD
- a palliative care specialist physician
- the palliative care program manager, from the Pharmaceutical Society of Australia
- a social worker supporting the Refugee Transition to General Practice, Refugee Health Service, Mid North Coast LHD.

A thematic analysis of this information was conducted to identify key trends, recurring issues, system enablers and barriers and areas of unmet need. Bringing together several data sources enabled triangulation of findings, strengthening the evidence base and ensuring that multiple perspectives were captured. This combined evidence forms the foundation for identifying key themes and priority areas outlined in the following sections.

5. Socio-demographics of the North Coast region

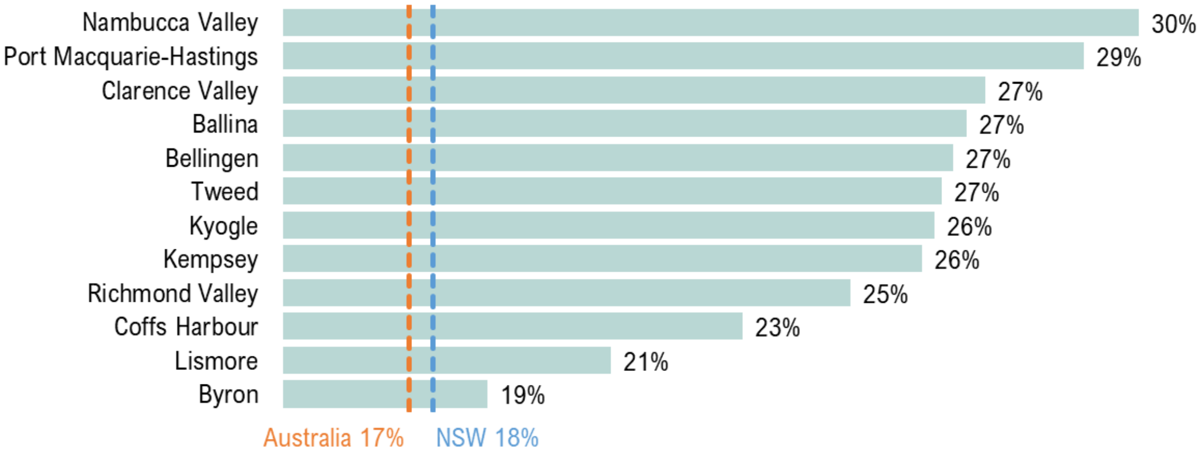
The North Coast is home to an ageing population who experience chronic health conditions at higher rates than the state and national averages. As people live longer and with complex health needs, they require more coordinated care and earlier support to stay well at home.

The North Coast experiences high levels of socioeconomic disadvantage and persistent barriers to access health care services, associated with regionality, limited transport, service availability and workforce distribution. These make it hard for people to receive care in the right place at the right time, increasing the likelihood of preventable deterioration, presentations to emergency department and avoidable hospitalisations. These compounding factors drive the growing need for coordinated, high-quality palliative and end-of-life care across primary, community and residential aged care settings on the North Coast.

In structural terms (the proportion of people in each age group) the North Coast region has a population older than NSW and Australia. As per the last Census (2021) the proportion of people aged 0-24 and 25-44 years on the North Coast was lower than both the NSW and Australian averages, whereas the proportion of people aged 45-64 and 65 and older was higher than both NSW and Australia (ABS, 2021).

Figure 1: Proportion of residents aged 65 years and over

The North Coast has a larger proportion of residents aged 65 and over than NSW and Australia



Source: ABS, 2021

In numerical terms (the number of people in each age group) Tweed, Port Macquarie-Hastings and Coffs Harbour local government areas (LGAs) have the highest number of people aged 65 years or older. Growth in both the proportion and number of older residents, particularly in the LGAs of Nambucca Valley, Port Macquarie-Hastings, Clarence Valley and Tweed, will continue to drive demand for palliative and end-of-life care services. This trend will place additional pressure on the primary care, aged care, and palliative care workforce in the years ahead.

6. Chronic disease

Prevalence of chronic conditions

On the North Coast, a higher percentage of people experience chronic health conditions than in NSW and Australia. Chronic conditions are a major cause of ongoing ill health, disability, and premature death. These diseases are characterised by long duration and persistent effects (AIHW, 2024). The most common chronic conditions on the North Coast are mental health conditions, asthma, arthritis, diabetes, cancer, and heart disease. Among people aged 65 years and older, these conditions remain prevalent, and others increase substantially, such as arthritis, heart disease, cancer, lung conditions, stroke, dementia, and kidney disease (ABS, 2021). Chronic conditions that become life limiting would benefit from a palliative care approach.

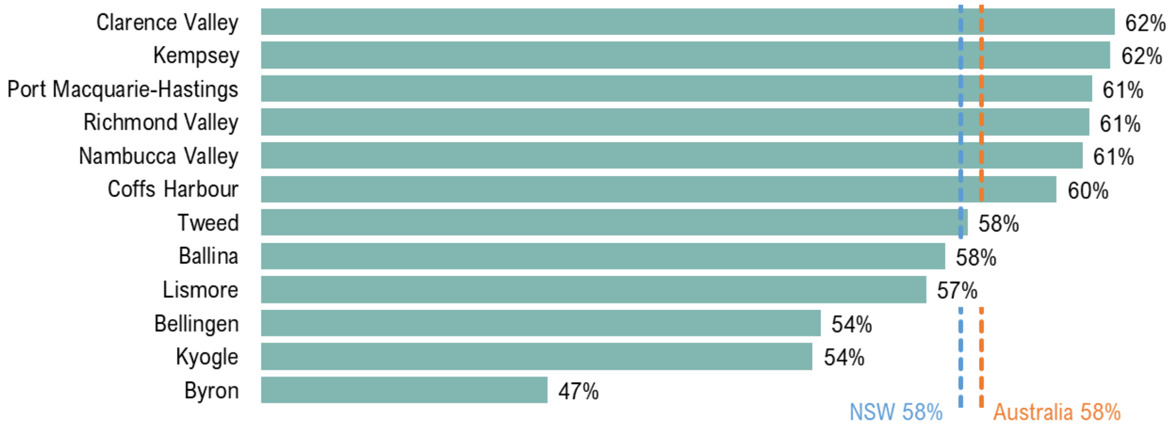
Figure 2: Proportion of people living with a chronic condition

The percentage of people of all ages living with a chronic condition on the North Coast (59%) is higher than NSW and Australia, and varying across LGAs

Source: ABS, 2021

Figure 3: Proportion of people aged 65 and older living with a chronic condition

The percentage of people aged 65 and older with a chronic condition on the North Coast (59%) is slightly higher than NSW and Australia, with 6 of the 12 LGAs above the state and national benchmarks



Source: ABS, 2021

People with chronic conditions are more likely to experience multimorbidity (2 or more chronic conditions) and/or polypharmacy (5 or more medications including prescribed, over the counter and complimentary medications) (AIHW, 2021; RACGP, 2019).

On the North Coast, a higher percentage of people live with multimorbidity and/or polypharmacy. In 2023, 17% of active patients of general practices across the North Coast had multimorbidity, and 13% had both multimorbidity and polypharmacy (PATCAT, 2023).

As people age, the combination of multiple chronic conditions increases the complexity of care needs. This underscores the value of a palliative care approach, which supports symptom management, care coordination, and quality of life for patients, families and their carers alongside ongoing treatments and throughout end-of-life care journeys.

Dementia prevalence and implications

Dementia is a progressive, life-limiting condition and a leading cause of death nationally and on the North Coast (AIHW, 2025). Unlike many other chronic illnesses, dementia can follow a long and unpredictable trajectory, often requiring years of differing levels of support including palliative care. This creates complex and prolonged care needs, including assistance with daily living, management of behavioural and psychological symptoms, and ultimately end-of-life care. Communication difficulties caused by cognitive decline can make it challenging for people with dementia to express symptoms or preferences, increasing the risk of unmet needs and underscoring the importance of early ACP. In 2024, 2.5% of North Coast residents were estimated to be living with dementia, which was considerably higher than the 1.7% NSW-wide and 1.6% for Australia (Dementia Australia, 2025). This reflects the region's ageing population and the growing need for tailored, coordinated support across health and aged care settings.

Figure 4: Proportion of residents with dementia

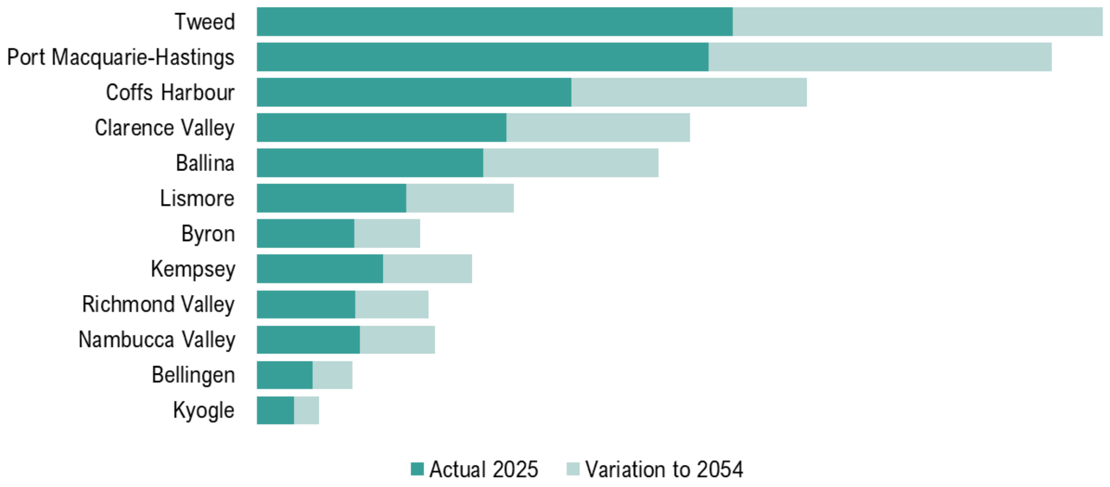
The proportion of residents living with dementia on the North Coast (2.5%) is higher than NSW and Australia

Source: Dementia Australia, 2023

The number of people estimated to be living with dementia on the North Coast is projected to increase by 80% to 2054, a little less than the projected increase in NSW (83%) and less than the Australia rate (93%). On the North Coast, Tweed, Port-Macquarie-Hastings and Coffs Harbour LGAs are projected to have the highest number of people living with dementia by 2054. The relative increase in people living with dementia is highest for Tweed (83%) and Ballina (82%) (Dementia Australia, 2025). This will place additional pressure on palliative and aged care services in the North Coast region.

Figure 5: Number of people living with dementia

Of all LGAs on the North Coast, Tweed has both the highest number of people living with dementia in 2025 and the largest projected growth to 2054



Source: Dementia Australia, 2023

The demographic and chronic disease health trends make the North Coast one of the most palliative-care-intensive regions in NSW. Most people with a life-limiting condition can be supported through generalist palliative care provided by general practitioners (GPs), nurses, allied health professionals and residential aged care homes (RACHs), with specialist palliative services reserved for complex cases.

The NSW Health End-of-Life and Palliative Care Framework 2019–2024 (NSW Health, 2019) and the National Palliative Care Standards (Palliative Care Australia, 2025) provide a shared vision for best practice, emphasising person-centred, coordinated and equitable care across primary, aged and community sectors. Alignment with these frameworks is essential to achieving the GCfAHPC program objective of safe, quality palliative care for at home.

7. Themes informing the Greater Choice for At Home Palliative Care program

This needs assessment outlines local needs, insights and opportunities across 4 interrelated themes:

- **Theme 1: Building capability and confidence in the workforce**
- **Theme 2: Strengthening community understanding and carer support**
- **Theme 3: Embedding equity and cultural safety**
- **Theme 4: Strengthening systems through data, integration and technology**

Together, these themes give effect to the GCfAHPC program objectives:

- improve workforce and community awareness and access to safe, quality palliative care at home and support end-of-life care systems and services in primary health care and community care

- enable the right care, at the right time and in the right place to reduce unnecessary hospitalisations
- generate and use data to support continuous improvement of services across sectors
- use available technologies to support flexible and responsive palliative care at home, including in the after-hours period.

This approach is designed to support the development of targeted, evidence-based activity work plans and ensure alignment with the GCfAHPC program logic (see Appendix 1 – GCfAHPC program logic).

The success in improving access to safe, quality palliative care on the North Coast relies on 2 mutually reinforcing pillars – a confident and competent, connected workforce and an informed, empowered community. Strengthening awareness, capability, and navigation across workforce and community lays the foundation for all other GCfAHPC objectives.

Theme 1: Building capability and confidence in the workforce

Workforce landscape

Demand for palliative and end-of-life care will continue to increase across the North Coast region as its population grows and ages and the working age cohorts decrease. In 2022-23 the North Coast region had the second highest rate of palliative care-related admitted hospitalisations out of the 31 national PHN areas, at 58 per 10,000 people, above the Australian rate of 39 per 10,000.

Reflective of the ageing structure of the North Coast regions, the rate of non-admitted palliative care service events on the North Coast in 2022-23 was 442 per 10,000 population, above the national rate of 293 per 10,000. A palliative care service event is defined as an interaction between a patient and their healthcare provider with the goal of optimising their quality of life. Proportionally, a substantial majority of admitted and non-admitted hospital events were for people 75 years and older on the North Coast (AIHW, 2025), with nearly the same number of palliative care hospitalisations for people aged 55-74 years (10,985 to 11,177), indicating high need for both age cohorts.

Capacity for hospice and hospital-based care is limited and varied. On the North Coast, the Northern NSW LHD and Mid North Coast LHD provide palliative care services across a combination of hospital, community, and outreach settings. Both LHDs face challenges in meeting growing demand due to the ageing population, high rates of chronic conditions and complex care needs (see section 5. Socio-demographics of the North Coast region). There is one alternate community hospice complementing LHD and community palliative care health teams, a 4-bed volunteer run facility located in Murwillumbah. The service is donation-based or free depending on patient means (Tweed Palliative Support Inc., 2025)

Across the North Coast, palliative care increasingly relies on a generalist workforce working alongside specialist teams. The specialist palliative care workforce (inclusive of medical, nursing, and allied health) on the North Coast has grown substantially over the past decade, with 19 full-time equivalent (FTE) specialists per 100,000 residents in 2023, higher than NSW (12 per 100,000) and Australia (13 per 100,000) (DHDA, 2025). This represents a 79% increase since 2013; This growth is uneven. Some LGAs, such as Bellingen (104 FTE per 100,000), have experienced significant expansion, while others like Richmond Valley and

Kyogle have zero FTE palliative care specialists[1], highlighting persistent geographic inequities relating to a lack of health and aged care infrastructure.

GPs are frequently the first point of contact for people who may benefit from palliative care; the distribution of GPs is unequal across the region. In 2022, the highest GP FTE rates per 1,000 residents were in Ballina (1.6), Byron (1.5), and Port Macquarie-Hastings (1.5), while the lowest were in Kyogle (0.7), Clarence Valley (0.7), and Nambucca Valley (0.9). These LGAs have experienced 26–42% declines in the number of GPs between 2019 and 2022. People in these areas can experience greater disadvantage due to lower SEIFA scores, higher levels of socioeconomic disadvantage, and more limited access to services., Community consultations and the Better Health Community Survey[2] highlighted difficulty in accessing GP appointments, with 54% of North Coast residents reporting it was "hard" or "very hard" to see a GP in 2024.

As the population ages and hospital capacity is stretched, more people are spending their final months within residential aged care homes (RACHs), relying on staff who may not see themselves as palliative care providers. In 2021 the Royal Commission into Aged Care Quality and Safety reported that too few people in aged care receive evidence-based palliative care and identified the provision of palliative care within the sector as a priority for immediate attention (Australian Government, 2021). Capability and confidence across RACHs nurses and care staff vary widely, underscoring the importance of consistent education, specialist support, and clear escalation pathways. Strengthening generalist capability is therefore a regional priority as chronic and life-limiting conditions rise.

The Palliative care clinician survey[3], undertaken by HNC between May and June 2025 highlighted a number of strengths and areas for targeted generalist workforce development. While 50% of clinicians felt confident providing palliative care, 33% were not confident referring patients to specialist services – citing unclear pathways, lack of established relationships with palliative care teams, and limited opportunities to collaborate. Clinicians reported low confidence in navigating support for patients receiving services from Department of Veterans Affairs (DVA), the National Disability Insurance Scheme (NDIS), or My Aged Care services (42% not confident) and discussing voluntary assisted dying (VAD) (42% not confident). Half of clinicians occasionally discussed ACP with patients during consultations – citing barriers such as lack of time, information, and stigma. Furthermore, 42% were not aware of upcoming changes to support-at-home care packages. These demonstrate the need for clear, ongoing communication and professional development for clinicians to ensure patients have access to quality palliative care.

Workforce wellbeing

Delivering end-of-life care is emotionally demanding, with high rates of staff burnout straining workforce sustainability. Experiences of burnout were reported by 44% of specialist palliative care workers and 41% of aged care staff in the Palliative Care Australia National Workforce

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[1] Stakeholders from the LHDs have identified potential inaccuracies in workforce data due to data suppression, which applies where the FTE is less than 3; therefore, figures should be interpreted with caution.

[2] Better Health Survey response rate n=3,328

[3] Palliative Care Clinician Survey response rate n=17

survey[4]. The Wellbeing in Palliative Care Workforces report, drawing on the national workforce survey[5] findings, highlights widespread burnout across both palliative and aged care sectors. Among specialist palliative care professionals, 80% reported heightened workplace stress or anxiety in the past year. One respondent noted, “Emotional burnout from working at capacity too long and often” capturing the strain placed on the workforce. Many staff reported difficulty maintaining personal-professional boundaries when regularly confronted with death and dying (Palliative Care Australia, 2025)

> *How a person dies can affect the wellbeing of others. Witnessing different traumatic dying processes can be very traumatic, particularly for the family, but also for the nurses involved. Good palliative care services should be available for everyone.* - Palliative Care clinician survey respondent

Consultations led by HNC locally validated these themes. Clinicians described the emotional load, workload pressures and system complexity as barriers to delivering the standard of care they aspire to. Without targeted support for wellbeing and development there is a risk of reduced retention, lower uptake of palliative approaches, and fewer ACP discussions. For RACHs staff, the emotional impact is amplified by supporting residents and families through deeply personal transitions, often with limited access to supervision, training or after-hours clinical support. Strengthening their capability and wellbeing is central to delivering safe, consistent palliative care and to ensuring that both residents and families feel supported when palliative conversations arise.

Role of general practitioners

General practice plays a central role in identifying individuals who may benefit from a palliative approach, particularly where long-standing patient-GP relationships exist. GPs facilitate transitions from chronic disease management to palliative and end-of-life care, often coordinating care across settings including home and residential aged care.

GPs highlighted the value of timely access to specialist palliative care clinicians for advice on symptom management and treatment decision-making. Shared care arrangements and timely specialist advice on complex issues – where GPs remain the primary provider with specialist input as needed – are considered important for effective care and enable patients to remain in the community, improve symptom control and reduce unnecessary hospital admissions.

The Royal Australian College of General Practitioners (RACGP) state ACP should be incorporated into routine general practice, recognising that GPs' long-term trusted relationships with patients positions them ideally to initiate and promote discussions about future healthcare preferences (RACGP, 2023; RACGP, 2019). Coordination and referral in generalist palliative care involves GPs working collaboratively with community nurses,

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[4] Survey of the National Palliative Care Workforce Across Health and Age Care Settings response rate n=1,400

[5] National Palliative Care Workforce Survey response rate n=1,400

specialist teams, hospitals, aged care facilities, and carers, ensuring ongoing communication and integration (van Gaans, Erny-Albrecht, & Tieman, 2022).

There are challenges to this approach particularly in regional areas. High turnover of GPs, an ageing workforce, and low GP FTE rates mean many do not have the relationships with patients that they once had, nor the time to spend with patients. Time to engage with and support patients was reported as a major barrier, exacerbated by a lack of Medicare billing codes for support and consultation around ACP and ACD.

One GP shared how they successfully integrated ACP discussions into practice templates and chronic disease planning discussions. They flagged an opportunity to further educate GPs around the successful use of standard consultation items for ACP discussions. Others identified an opportunity for further education about using standard consultation items to support ACP within routine care.

Overall themes across consultations with service providers identified a variability in knowledge and confidence around palliative care including when and how to start conversations. While ACP and palliative care are not directly funded, they can be supported through existing MBS items embedded in broader care planning and assessment processes.

A common misconception remains that palliative care is only for people with cancer; in reality, it is an approach suitable for anyone living with a life-limiting illness including dementia, chronic heart, lung, kidney, or neurological conditions, where early engagement can significantly improve quality of life and coordination of care. Opportunities for early intervention may be missed, leading to increased hospitalisations, unmet care needs, and limited access for people with non-cancer conditions who would benefit from palliative care support (University of Wollongong, 2023).

The introduction of VAD in NSW added another layer of complexity. The Voluntary Assisted Dying Act 2022 came into effect on 28 November 2023, enabling eligible people to access VAD as one of several end-of-life pathways. Although the palliative care clinician survey had a small sample size with 17 validated responses, it does indicate that clinicians have low confidence in discussing VAD with patients, families and carers. Respondents reported limited understanding of the legal framework, insufficient training, inexperience in VAD-related discussions and ethical or emotional concerns. While many clinicians encounter VAD queries at least occasionally, most identified a need for locally relevant training, clear guidance on roles and processes, and practical communication tools. Building GP confidence in palliative care and VAD conversations is a workforce priority.

Role of residential aged care homes

RACHs are often overlooked within the broader discussion of generalist workforce capability, despite caring for a growing share of people at the end of life. As the population ages and hospital capacity is stretched, more people are spending their final months within residential aged care, relying on staff who may not see themselves as palliative care providers. highlighting the need to have a consistent palliative approach to care within RACHs.

The Royal Commission into Aged Care Quality and Safety (2021) identified the delivery of palliative care within aged care as an urgent national priority, finding that too few residents receive evidence-based, person-centred end-of-life care. The revised Aged Care Quality Standards (2025) introduce a specific outcome, the Standard 5.7 Palliative care and end-of-life care, requiring providers to recognise and address the needs, goals and preferences of individuals at the end of life (Aged Care Quality and Safety Commission, 2021).This shift formally acknowledges what is already in practice – that aged care staff play a critical role in helping residents live well until death, and that they require support, training, and confidence to do so.

Across the North Coast, feedback from consultations with aged care providers and regional managers indicates that understanding and confidence in delivering a palliative approach remain variable. Many nurses and care workers report uncertainty about symptom management, anticipatory prescribing, and how to hold conversations about dying in ways that are compassionate and appropriate. In some facilities, palliative care is still perceived as something that happens elsewhere (in hospitals or under the direction of external specialists) rather than as an integral part of daily care. RACHs increasingly provide end-of-life care but often rely on emergency departments for after-hours support, resulting in transfers that may be distressing and inconsistent with resident wishes.

Families often describe being unprepared for the dying process, unsure of what palliative care means or when it begins, this lack of confidence can create anxiety and confusion. When clinicians avoid or delay conversations about ACP, families may miss the opportunity to make informed decisions about whether a resident wishes to remain in their home or be transferred to hospital. Without early, open conversations, hospital transfers can occur in crisis, contrary to the resident's wishes. Supporting families and carers to understand that palliative care and ACP are about living well until death by choosing the conditions for comfort, dignity and control, and is essential to changing these experiences.

Strengthening RACHs workforce capability will be essential to enabling residents to remain in their preferred place of care, reducing avoidable hospital transfers and ensuring high-quality, person-centred support at end of life. HNC recognises the importance of working in partnership with Northern NSW LHD and Mid North Coast LHD to optimise aged care services and support older people in the community to access care in the right place at the right time.

As part of the prior GCfAHPC program, HNC is leading the design and implementation of the Integrated Model of Support (IMoS) for Residential Aged Care, which aims to strengthen coordination and support so that residents receive timely, appropriate care in familiar environments. IMoS aligns with the revised Aged Care Quality Standards and focuses on building capability within RACHs through education, tools to recognise and respond to deterioration, clear escalation pathways and direct links with LHDs outreach and primary care.

Complementing this model, the Building Nurse Capacity in Primary Care program aims to build the knowledge, skills and confidence of nurses to provide person-centred care to support an individuals' palliative and end-of-life care needs. At the time this needs assessment was completed, the program was in pilot phase in 5 general practices and 5 RACHs. Education modules and tools include ACP processes, recognising and responding to deterioration, anticipatory practices and the use of telehealth. These models aim to improve patient outcomes, enhance care coordination, and increase the overall capacity and responsiveness of primary care teams.

Part of the Building Nurse Capacity in Primary Care program, a key regional initiative is the Deteriorating Resident Triage Tool (DRTT), which provides structured clinical guidance for assessing and triaging unwell residents, particularly after hours. The tool prompts consideration of goals of care during decision-making and supports data collection on deterioration. Mid North Coast LHD has embedded the DRTT into RACH triage checklists, supporting consistent use, contributing to regional data collection and informing regional planning.

RACHs across the region are already demonstrating readiness to embrace their role in palliative and end-of-life care. With the right support, they can provide high-quality, compassionate care that honours the choices made by residents and reduces unnecessary hospital transfers. Investing in the knowledge, confidence, and connectedness of RACHs teams will ensure palliative care becomes a natural and valued part of everyday care and not an afterthought.

Role of allied health professionals

Pharmacists and other allied health professionals play an essential yet often under-recognised role in community palliative care. Access to medications, particularly after-hours, was identified as a barrier that can affect timely, home-based palliative care. Pharmacists can address this, yet there is a need for pharmacist education on palliative care (Hava, 2025).

> *As pharmacists, we don't learn a lot about palliative care in our undergraduate course. And the majority of pharmacists haven't done any extra palliative care education since their university days.* Senior Pharmacist

To address this, the Pharmaceutical Society of Australia (PSA) developed the ASPIRE Palliative Care Foundation Training Program. Launched in May 2025, the program provides online accredited training modules to build knowledge and skills. In addition, the National Palliative Care project *caring@home* has developed a set of resources and tools for pharmacists around core palliative care medications, including how to update this so they can be located on healthdirect. There is an opportunity for HNC to support and promote these programs and resources to build local workforce capacity.

Social workers play a key role in helping patients and families talk about what matters most, understand their options, and complete ACP documents. Without this support, families may feel stressed and unsure when making decisions, and care may not match the person's wishes. When social workers are not part of the care team in general practice, ACP is often delayed or incomplete.

Research shows that social workers improve ACP by starting conversations, explaining advance directives, and linking people to community services (Boucher, 2020; Rao, Guyer, Almhanna, & Baum, 2021).They help with cultural and emotional needs, which makes ACP more inclusive and effective (Boucher, 2020). Without them, patients may miss out on referrals to palliative care or social supports, which can lead to unnecessary hospital visits and care that people do not want (Rao, Guyer, Almhanna, & Baum, 2021; Waldrop & Meeker, 2012).

Continuing to build workforce capability

Recognising the need to build the capacity of the generalist workforce, during the first 3 years of GCfAHPC, HNC has introduced several initiatives aimed at strengthening workforce capability in palliative and end-of-life care.

HealthPathways are a core enabler. The development of Early Intervention in Palliative Care, Anticipatory Prescribing and updated ACP pathways provide clinicians with clear, standardised guidance on ACPs, ACDs, anticipatory prescribing, and palliative and end-of-life care. These pathways enable a more consistent practice, clearer referral pathways and earlier patient engagement, while supporting ACP documentation that is comprehensive, accessible and available through systems such as My Health Record.

Previously, HNC has facilitated GP breakfast sessions to share information and foster collaboration between primary and specialist care providers. GPs reported that these sessions were valuable for networking and practical learning and suggested that similar forums would be beneficial for ongoing palliative care education, case-based discussion and peer support.

Strong partnerships between GPs, LHDs, allied health professionals, and specialist palliative services are vital to achieving seamless transitions between care settings, supporting timely responses to changing needs, and ensuring equitable, high-quality palliative care. Focusing on workforce capacity-building and integration across both primary and specialist care, should be continued in the future planning and delivering of the GCfAHPC program.

Care coordination

Current palliative care services often lack sufficient integration and coordination, with challenges in navigation and transitions through care providers and settings. Community feedback gathered during National Palliative Care Week 2025 highlighted the ongoing need for clear, trusted pathways to help people understand what palliative care is, how to access it, and how different parts of the system connect. Improved wayfinding and coordination are essential to ensure awareness translates into timely engagement with appropriate services, particularly for those with chronic or life-limiting conditions who may not identify themselves as *'palliative.'*

In consultation, a palliative care physician emphasised that effective coordination and integration of services is critical, suggesting a dedicated coordinator role could support patients, families, and practitioners to navigate the system. Streamlined pathways and clearer communication between providers are essential to improve continuity, accessibility, and the overall patient and family experience. Without these, people may avoid services if they are perceived as too complex or fragmented, which can restrict choices and affect preferences for place of care and place of death.

Theme 2: Strengthening community understanding and carer support

Although about 70% of Australians prefer to die at home, only 14% do (Grattan Institute, 2024). Increasing community awareness about palliative care supports people's ability to advocate for them and their loved ones to ask for and receive palliative care. Communities, families and carers are central to enabling people to remain in the place they call home at the end of life. Many people continue to associate palliative care solely with imminent end-of-life rather than understanding it as a holistic approach that improves quality of life earlier in the course of illness (Trivedi, et al., 2019). Enhancing opportunities for community members to engage in palliative care and advance care planning within everyday life is suggested to improve death literacy and reduce stigma and fear of palliative care (Black, Hasson, Slater, & McIlfatrick, 2024).

Building community understanding and early planning

Avoidable hospital admissions often reflect gaps in early identification of palliative needs, limited care planning or inadequate support for deterioration at home or in RACHs. Based on workforce capacity and capability (see Theme 1: Building capability and confidence in the workforce) there is a compelling need to embed community awareness to help address these issues.

ACP and ACDs are central to aligning care with people's values and enabling home-based care. Despite recognised benefits, ACP completion remains low nationally and locally. A survey by Advance Care Planning Australia in 2025 found that 33% of adults had undertaken any form of ACP and 19% had discussed their future healthcare with someone else. Even fewer had completed formal documents –13% had formally appointed a substitute decision-maker and 6% had completed an ACD. Most ACP conversations occur within families. Discussions typically take place with a partner or spouse (60%), adult children (29%), parents (18%), close friends and siblings (both 17%), while engagement with health professionals remains uncommon (12%). Despite this, 73% of Australians are open to having ACP conversations and recognise the benefits, particularly for their loved ones ACD (Advanced Care Planning Australia, 2025).

Dementia and multimorbidity further amplify the need for early planning for palliative and end-of-life care. As dementia progresses, decision-making capacity becomes increasingly compromised, making ACP more complex. Family members and carers are often required to take on a greater role in decision-making on behalf of the person with dementia (Dening, Sampson, & Vries, 2019).

During consultations with HNC, service provider participants highlighted that people with dementia are often not provided with opportunities for early intervention and timely referral, which reduces the ability to commence ACP during the early stages of diagnosis. Specialists emphasised the importance of ACP and ACDs for both individuals and families in reducing distress and supporting preferences to remain at home or in residential aged care. Without early planning, carers face higher stress and people living with dementia are more likely to enter residential care earlier or present to emergency departments. Participants emphasised the importance of having these conversations early to support people living with dementia to have their preferences understood and respected throughout the course of their illness.

Through previous GCfAHPC funding, initiatives to build community awareness and capacity have included engagement activities during National Palliative Care Week, Dying to Know Day, and Advance Care Planning Week. HNC commissioned Palliative Care NSW to facilitate a series of Community Conversations, resulting in 10 sessions held across the North Coast region between June 2023 and June 2024, engaging 271 participants. Across all sessions, more than 90% of participants reported improved knowledge and confidence in palliative care and advance care planning. In addition, Palliative Care NSW delivered PalliLEARN, a series of 8 introductory online palliative care courses, which highlighted the community's willingness to learn when information is accessible, relevant, and person-centred.

These courses attracted 141 registrations from the North Coast region. These sessions were delivered in collaboration with local LHDs palliative care teams, strengthening and standardising messaging while building awareness of local services and supports. This approach helped avoid duplication, connected participants with their local services, and created opportunities to normalise conversations about death and dying. It raised awareness of ACP, ACDs, and local service and support options. Increasing understanding across the community and improving documentation practices create opportunities for early referrals, more open discussions between patients and families, and better access to supports.

Of those participants, 98% reported satisfaction and confidence in applying what they learned, while 91% noted improved knowledge. Participants consistently reported improved understanding of the importance of ACP but a lack of confidence in completing ACP documentation. While the sessions reinforced the value of ACP, many found the documentation overwhelming and expressed a need for practical support to complete it.

> *Good introduction, but I need to now learn more + discuss + implement actions.*
> Wauchope participant

This highlights the importance of pairing awareness with navigation assistance, so people can translate learning into action. Barriers such as uncertainty about how to start, perceived complexity, and potential cost highlight the need for greater awareness, guidance, and support for community members/people in the communities.

ACP and ACDs, including the vital steps of discussions and sharing with loved ones, carers and medical practitioners, begin with normalising death and dying as part of life in our families and communities.

Carers support

On average, a person with a life-limiting illness will spend only about 5% of their time with a medical practitioner, with the remaining 95% spent at home and in the community (Auon, Richmond, Rumbold, Gunton, & Noonan, 2022). The presence of a willing and supported carer is one of the strongest predictors of home death for people with life-limiting illness and is vital to sustaining home-based care and preventing avoidable hospitalisations.

Despite their vital role, carers often describe feeling underprepared, isolated and uncertain about how to manage the realities of caring for someone at the end of life. The emotional and physical toll can be profound. Many carers lose confidence over time and feel unable to continue care at home, even when home is the person's preference. Unsupported carers are more likely to experience burnout, leading to premature institutionalisation or hospitalisation of the person they care for and undermining the preference of most Australians to receive end-of-life care at home (van Gaans, Erny-Albrecht, & Tieman, 2022). Carers need reassurance, guidance and opportunities to talk about what death and dying will look like, so they can prepare emotionally and practically. GPs, nurses and community services play a crucial role in building this confidence by providing honest, compassionate education about what to expect, how to manage symptoms and who to contact for help. By ensuring medical practitioners provide care elements such as medication, pain management, and support to understand and manage the dying processes allows carers and families to spend time with their loved one.

Investing in carer wellbeing is both compassionate and cost-effective as informal and hidden carers contribute billions of dollars in unpaid care annually, reducing demand on hospitals, aged care and other health services (Australian Government, 2023). In 2021, 11.3% of people on the North Coast provided unpaid assistance to a person with a disability, health condition or due to old age (ABS, 2021). Carers strengthen communities by fostering connectedness, enabling family and cultural responsibilities, and supporting the emotional and practical needs of patients. National resources such as *caring@home* offer accessible, evidence-based carer packs that explain practical symptom management, comfort measures and medication safety. Many carers remain unaware of these resources, particularly those not closely connected to formal health services.

Carers can experience substantial physical, emotional, and social burdens that considerably affect their own wellbeing and their capacity to provide quality care. The risk of death for a carer increases by over 60% in the 2 years after their caring role ends, in what is referred to as the ‘hang over effect’. Carers need comprehensive support and education that empowers them to provide care with confidence while safeguarding and promoting their own health and wellbeing (Palliative Care Australia, 2024). This reflects a public health approach, recognising the importance of supporting both patients and carers within the broader community context.

Compassionate communities

Across the North Coast, communities have expressed a clear need for more opportunities to talk openly about death, dying and bereavement. Many people want to know how to support neighbours, friends or family members approaching the end of life but do not know where to start. Community capacity, not just clinical services, is critical to sustainable palliative care.

The Compassionate Communities movement recognises that good end-of-life care extends beyond the health system. Compassionate Communities offer a framework for empowering local networks to support people through dying, death, caregiving and bereavement (PHPCI, 2025). These naturally occurring networks of support surround those experiencing dying and loss, complementing formal health and aged-care services (Palliative Care Australia, 2018).

The foundation of this approach lies in death literacy – the confidence, knowledge and practical skills that enable people to access, understand and act on palliative and end-of-life care options (Noonan, Horsfall, Leonard, & Rosenberg, 2016). Through education programs, death cafés, cultural events and training initiatives, communities can normalise conversations about dying, support ACP and provide practical help that reduces reliance on hospital-based emergency responses (Vitorino, Duarte, Ali, & Laranjeira, 2024).

Models such as the Compassionate Connectors trial (2020–2022), which trained local volunteers to walk alongside people living with life-limiting illness, demonstrate how informal support can reduce carer stress and reliance on hospital care. In Western Australia, participants experienced significant reductions in hospital admissions and days spent in hospital, alongside higher community engagement and wellbeing (Aoun, Bear, & Rumbold, 2023). Community-based models like Compassionate Connectors deliver substantial benefits for patients, carers and families – improving quality of life, reducing social isolation and increasing confidence in managing care at home. These models can lower costs and foster resilient community infrastructure that sustains itself over time (Aoun, Richmond, Rumbold, Gunton, & Noonan, 2022). Successfully implementing Compassionate Communities models is dependent on successful integration into policy frameworks and sustainable funding mechanisms that value community-based care (Palliative Care Australia, 2018; Aoun S., 2025).

Building community confidence in end-of-life care requires recognising the value of non-clinical support roles that sit alongside formal services. Within this context, end-of-life doulas are emerging as an important part of compassionate communities, offering presence, advocacy, and practical guidance for individuals and families navigating dying, death, and bereavement (Rawlings, Miller-Lewis, & Swetenham, 2018).

International models such as the Leeds NHS End-of-Life Doula Pilot (2024) demonstrated that end-of-life doulas can fill gaps in existing services, provide flexible person-centred support and receive positive feedback from families and clinical stakeholders (End of Life Doula UK, 2024; Borgstrom, Bashir, Pestano & Ramsey-Jones, 2023). End-of-life doulas can provide support through new My Aged Care Support at Home packages (introduced November 2025).

In Australia, there is no formal national pricing guide or regulations governing end-of-life doulas. Fee structures are typically negotiated privately, with many doulas charging hourly rates depending on location, experience, and complexity (Rawlings, Miller-Lewis, & Swetenham, 2018). In the context of ongoing workforce pressures in palliative care, doulas offer a supplementary workforce that enhances community capacity by providing practical, emotional, and relational support to families – working alongside, but not replacing, clinical services.

Theme 3: Embedding equity and cultural safety

Socio-cultural aspects need to be explored when developing strategies for engagement with all members of society (Black, Hasson, Slater, & McIlfatrick, 2024). Developing effective strategies for engaging all members of society in palliative care requires a nuanced understanding of the socio-cultural barriers faced by priority populations. Many groups experience greater challenges in accessing healthcare in general, and palliative care is no exception (Australian Government Department of Health, 2019).

Aboriginal and Torres Strait Islander peoples

Aboriginal and Torres Strait Islander peoples (Aboriginal peoples) on the North Coast continue to experience higher rates of chronic and life-limiting illness and earlier mortality than non-Indigenous Australians. These inequities are shaped by social and historical factors as much as by health conditions. The experience of serious illness, dying, and grief is deeply connected to culture, Country, and kinship. For many Aboriginal people, the concept of care extends far beyond the clinical care to a more holistic concept of social and emotional wellbeing that includes family, spiritual connection, and being able to remain on Country surrounded by community and culture.

Aboriginal peoples may have different experiences when accessing palliative care or when facing grief, death, and loss than non-Indigenous Australians. Cultural practices, traditions, and spiritual needs are central to care at the end-of-life, and it is important these are recognised and respected. These practices are diverse and not the same across all

Aboriginal communities. Open communication with the person and their family is essential to ensure cultural needs and individual preferences are understood and supported (Queensland Aboriginal & Torres Strait Islander Health Branch, 2015).The HNC region is on Githabul, Bundjalung, Yaegl, Gumbaynggirr, Dunghutti and Birpai Nations. Across these nations, community members and health workers consistently emphasise the importance of dying on Country and the distress that can occur when people must leave their community to receive care. Yet, limited outreach services, rigid appointment structures, and hospital-centric models often mean Aboriginal people are required to travel or engage with systems that feel unsafe or unfamiliar. There is a strong need for palliative and end-of-life care to be delivered within the parameters of connecting to Country through outreach, home visits and culturally appropriate care coordination.

Primary care providers play a central role in this but often report limited cultural capability and confidence in supporting Aboriginal patients and families at end of life. Building this capability – to listen, collaborate, and deliver care in culturally safe and flexible ways – is a key regional need. General practices and community providers require stronger partnerships with Aboriginal Community Controlled Health Organisations (ACCHOs) to ensure that care planning, communication, and follow-up are guided by Aboriginal knowledge systems and family structures. Evidence demonstrates that services led or guided by ACCHOs improve health outcomes for First Nations communities by being prevention-focused, culturally safe, and free from racism (Davy, Harfield, McArthur, Munn, & Brown, 2016). Carers and families, often part of broader kinship networks, are central to the care of Aboriginal peoples at the end-of-life. The practical, emotional and spiritual burden they carry is magnified when services are not responsive to community rhythms or when formal supports do not recognise shared caring responsibilities within extended families. Culturally safe models must acknowledge this collective approach to care, ensuring support extends to the whole kinship group rather than just the primary carer.

HNC acknowledges that achieving culturally safe, community-led palliative care requires genuine partnership. The organisation’s work takes place across 6 Aboriginal nations, and its ongoing partnership with ACCHOs provides the foundation for understanding what culturally safe, community-driven care looks like in practice. At time of completing this needs assessment, the Bullinah Aboriginal Medical Service was undertaking a palliative care needs assessment focused on Aboriginal peoples. HNC is committed to drawing on that work to guide and strengthen future planning activities. These partnerships sit within broader agreements such as the Mid North Coast Accord and the Northern NSW Aboriginal Partnerships Agreement, which call for integrated, respectful, and trauma-informed care across the primary and acute systems.

Culturally and linguistically diverse population

The North Coast region is home to people from a wide range of culturally and linguistically diverse (CALD) backgrounds, including refugees, seasonal farm workers, and international students. The CALD population is growing, and there is a need for more detailed and localised data to better understand and respond to the unique needs of these communities. For many of these residents, particularly older migrants, the experience of serious illness, dying and death is influenced by cultural values, language, and migration history in ways that differ from mainstream expectations of care. Different aspects of a person’s identity can expose them to overlapping forms of discrimination and marginalisation, highlighting the importance to consider intersectionality (along with diversity).

For people from CALD backgrounds, the concepts of palliative and end-of-life care may not always align with their cultural understandings of illness and dying. Discussions about death can be considered taboo in some cultures, while in others family members play the primary role in decision-making rather than the individual. These cultural differences can create barriers to accessing care or completing ACPs, especially when combined with language challenges, limited interpreter access and low awareness of available services. Many rely on family and kinship networks for care, often in multigenerational households, but may have limited knowledge of how to navigate the health system.

Health information is frequently only available in English, and even when interpreters are used, short consultation times and unfamiliar terminology make it difficult for families to express values and preferences. Communication barriers can lead to distress and misunderstanding at critical points, particularly when symptoms worsen or decisions about hospital transfer arise. For some, cultural norms around modesty, gender, and privacy influence how and where they prefer to receive care. Others feel discomfort engaging with hospital or residential care systems due to past trauma or fear of discrimination. In such circumstances, home becomes the most trusted and comfortable place to receive care, but the systems that support home-based palliative care are often not equipped to meet their needs.

HNC supports initiatives to improve access to primary care, including funding a social worker to work across 3 general practices. This role aims to link people from settlement services into primary care. further support is needed to meet the specific needs of CALD communities, particularly for those requiring palliative care.

The experience of carers in CALD families is distinct. Caring responsibilities are often shared across extended family or community networks, but this informal support may not be visible to health providers. Carers may experience emotional strain, isolation, or confusion navigating clinical and administrative requirements in a second language. Their capacity to provide care at home can be limited by economic pressures, visa restrictions, or lack of culturally safe respite options.

The diversity of languages, religions and traditions across the North Coast enriches communities but in turn complicates the delivery of equitable palliative care. Without culturally and linguistically appropriate communication, many people are excluded from fully understanding or exercising choice about their care. As the population continues to grow and age, understanding where CALD communities live, what languages are spoken, and how cultural beliefs shape experiences of illness and dying will be critical to ensuring that everyone, regardless of background, can access quality palliative care at home.

LGBTQ+ communities

The North Coast region has limited local data on the experiences of LGBTQ+ people with palliative care. Evidence from research undertaken by Roberts et al (2022) provides insights that can inform planning and service development in the region. The study drew on a community survey[6] and follow-up interviews with LGBTQ+ people, capturing a range of perspectives and experience with palliative care (Roberts, et al., 2022). The study explored the perspectives of LGBTQ+ community members on palliative care in NSW.

Barriers to access for palliative care included:

- uncertainty about whether to disclose sexual orientation or gender identity
- limited awareness among staff of LGBTQ+ needs
- concerns about discrimination or substandard care
- conflict with family
- experiencing loneliness or isolation.

Enablers for inclusive palliative care included:

- access to inclusive information
- stronger engagement between services and LGBTQ+ communities
- non-discriminatory service delivery
- respectful person-centred approaches
- staff training on LGBTQ+ needs and issues.

While many participants reported positive experiences with palliative care, the findings indicate that LGBTQ+ people may face additional barriers to access such as fear of discrimination, previous negative experiences with healthcare providers, and limited recognition of diverse family and caring structures.

Ensuring services are inclusive, respectful, and responsive to diverse needs is an important consideration for planning services in the North Coast region. Resources such as the LGBTQI+ Inclusive Palliative Care eLearning, developed in partnership with palliative care experts and co-designed with LGBTQ+ communities across Australia, provide free training opportunities for health professionals to improve knowledge, inclusivity, and person-centred practice in palliative care. Incorporating such resources into staff development and service planning can help address barriers and support more inclusive care (LGBTQ+ Health Australia, 2025).

Theme 4: Strengthening systems through data, integration and technology

Technology is increasingly central to delivering flexible, person-centred palliative care, particularly in rural areas and outside standard business hours. Digital systems can assist improving communication between providers, strengthening continuity of care, and ensuring that people's care preferences are documented and respected. Variation in digital literacy, interoperability, and infrastructure continues to limit their potential to achieve these.

Digital pathways and clinical guidance

HealthPathways remain a cornerstone of consistent, evidence-based care across the region. At a systems level, HealthPathways support more consistent decision-making, clearer referral pathways and more coordinated care across primary, community and aged-care

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[6] LGBTQ+ community survey (n=419)

settings. Monitoring local use of pathways through analytics and responding to clinician feedback allows ongoing refinement and alignment with emerging evidence and local needs.

HNC has developed 3 new pathways to guide clinicians in identifying needs early, supporting nurse-led approaches and reducing preventable hospitalisations: Early Intervention in Palliative Care pathway, Anticipatory Prescribing pathway and Advance Care Planning pathway. The Northern NSW Expected Death at Home form was revised following feedback from GPs, ensuring it better meets the needs of clinicians and supports quality, coordinated care for patients at end of life. Collectively, these activities demonstrate a shift from ad hoc data use to a more deliberate, learning-system approach where feedback informs continuous quality improvement.

Data for continuous quality improvement

HNC undertakes a range of activities that generate data to inform service planning, commissioning, and quality improvement in palliative care. At present, data across primary, acute, and aged care sectors remains fragmented, which limits visibility on outcomes and opportunities for improvement.

General practice data offers opportunities to identify people who may benefit from a palliative approach earlier. The development of 4 recipes within the general practice clinical information systems enhances systematic identification and supports GPs to review patient needs proactively (Pencs, 2025). Embedding these datasets into routine workflows ensures timely referral, supports equity monitoring, and strengthens local quality improvement.

Complementing this, shared LHD data on RACHs resident transfers and palliative care presentations provides insight into escalation patterns, informing targeted education and anticipatory care planning. By analysing the drivers behind hospital presentations, HNC and its partners can identify opportunities for improvement in workforce and system, reducing preventable transfers.

At the national level, tools such as the Palliative Aged Care Outcomes Program (PACOP) and the National Palliative Care Collection (NPCC) enable benchmarking of symptom management, function and outcomes across services. Early pilots such as the NPCC, led by the University of Wollongong, equip practices with standardised screening and referral tools, generating consistent national data to guide improvement. Expansion of such frameworks to the North Coast would strengthen local benchmarking, enable data-driven decision-making, and enhance regional accountability.

Collectively, these initiatives reflect a shift from ad-hoc data use to a deliberate learning system, where insight and feedback actively inform continuous quality improvement.

Digital health platforms

Digital health platforms such as My Health Record (MHR) play a critical role in centralising information and storing advance care planning documents, giving patients and carers a way to ensure their wishes are available and accessible to providers across care settings.

> *My Health Record is our only source of information for a patient when they come in sick in the middle of the night. Having access to an advance care directive is*

probably the single biggest thing that could change our care for patients in the emergency department. Emergency Department consultant

Despite its value, provider consultations identified variation in MHR use due to differences in software integration, limited digital literacy, and unclear workflows. In addition, the quality and accessibility of ACP documentation is highly variable. To be effective, ACDs need to outline clearly and in detail a person's wishes. Some clinicians were unaware of upload processes or found them time consuming. Ensuring documents remain current is an ongoing challenge.

There is a need to standardise ACP documentation and storage approaches and support clinicians with practical guidance, clear workflows and training. Encouraging the use of existing Medicare health assessment and chronic disease items for ACP, coupled with workflow integration and training, can help normalise early palliative conversations and ensure that directives are easily retrievable when decisions need to be made.

Digital tools and virtual care

Advancing technology supports the opportunities for virtual care, increasing access to highly specialised services regardless of location. It is especially helpful for people living in rural and remote areas to access supports not readily available locally, reducing travel time and enabling timely care within the home. Data from the Better Health Community Survey (2024) shows strong community acceptance of virtual care: 62% of respondents had used telehealth and would be happy to do so again, while 24% had not yet used it but were open to trying. Telehealth supports consultations, clinical advice, education and carer engagement, helping to overcome geographical barriers.

Programs such as Queensland's Specialist Palliative Rural Telehealth Service (SPaRTa) demonstrate how structured telehealth can meet regional palliative care needs while supporting local clinicians with education and mentoring (Queensland Government, 2025).

Emerging virtual care models, including remote monitoring and virtual case conferencing, have the potential to enhance after-hours responsiveness and reduce unnecessary hospital transfers, particularly for RACHs residents and rural patients. Real-time access to advice from GPs and palliative specialists via secure messaging or video builds confidence among nurses managing deteriorating residents and supports continuity of care.

Pharmacy and medication access

Timely access to medications, particularly after hours, remains a barrier to home-based palliative care. Delays in accessing core symptom-management medicines can drive avoidable hospital presentations. Stronger coordination between pharmacies, prescribers and after-hours services, supported by e-prescribing and secure communication tools, can reduce these delays and help people remain at home in comfort and safety.

The growing availability of pharmacist-focused education such as ASPIRE, and national resources such as *caring@home* pharmacy tools presents opportunities for HNC to work with local pharmacies to embed palliative care competencies and strengthen their role in community-based care. Improving medication access will reduce unnecessary hospital admissions and increase the ability of people to remain at home in comfort and safety.

Emerging technology and artificial intelligence

The inclusion of artificial intelligence (AI) continues to evolve in health care settings, with increasing opportunities for it to support a palliative approach and improving end-of-life care. From prognostication and identifying who may benefit from palliative care to symptom assessment, documentation and workflow support, the use of AI is emerging and promising.

Early pilots and commentaries are exploring AI-enabled chatbots for caregiver Q&A, psychoeducation and navigation support, particularly in rural communities. Tools such as the Palliative Care Assessment Tool (PCAT) and adaptive ACP assistants show potential to identify needs earlier and support personalised care (Aged Care Research & Industry Innovation Australia, 2025). HNC is exploring AI-driven curation of person-centred digital resources to help community members find reliable, local information about services, supports and palliative care options. This responds directly to consumer feedback from 2025 consultations about difficulty finding accurate, consistent information.

While promising, these tools require robust governance and evaluation to ensure clinical safety, ethical implementation and equity of access. Ongoing monitoring of developments and careful identification of use cases where AI can safely enhance person-centred care will be important for the region's future planning.

8. Conclusion and opportunities

Ensuring equitable access and strengthening workforce capability will be essential to meeting the needs of an ageing population and a growing number of people living with chronic and life-limiting illness. Future efforts should continue to increase both community and workforce understanding of palliative care and ACP, embedding these as core components of holistic, person-centred care.

By harnessing the power of digital technology and data, fostering long-term community-based supports, and improving care coordination across care settings, we can enable people with life-limiting illness and their loved ones to receive the right care, in the right place, at the right time. Sustained investment through the GCfAHPC program provides a unique opportunity to embed these principles into practice, creating a more connected, capable and compassionate palliative care system for the North Coast.

The opportunities identified through this needs assessment to support a strong, sustainable and person-centred approach to palliative and end-of-life care are listed below in Table 1.

Table 1: Opportunities to enhance palliative care access and experience on the North Coast

Opportunity
Workforce
Continue to provide further education opportunities for the primary care workforce regarding the scope and processes related to generalist palliative care
Support general practitioners to integrate ACP discussions into consultations with patients
Provide further education and guidance for general practitioners around appropriate Medicare billing schedule items to use to bill for ACP discussions
Continue to host networking initiatives to bring together service providers to build partnerships and raise awareness of available resources
Encourage community pharmacists to undertake palliative care training programs
Enhance the capacity and capability of community pharmacists to support palliative care and building awareness and expanding access for health professionals and community members
Establish multidisciplinary teams to helps general practitioners and patients coordinate and navigate supports and access resources
Continue to support nurses to build knowledge, skills and confidence to provide person-centred care to support and individuals' palliative and end-of-life care needs through the *Building Nurse Capacity in Primary Care Program*
Enhance palliative care knowledge and skills within residential aged care homes to support residents in place and minimise unnecessary hospital transfers
Strengthen the generalist workforce's capability in anticipatory prescribing and care planning to prevent unnecessary hospitalisations and ensure timely, appropriate care in community and aged care setting
Community
Continue to provide further education and guidance for community members to learn how to complete ACDs

Continue to provide further education for community members around what constitutes palliative care, the stage of life it relates to, and how it can improve quality of life
Provide further support to carers both during and after someone has received palliative care
Strengthen death literacy initiatives and models of compassionate communities to complement clinical services for palliative and end-of-life care
Ensure approaches for palliative care are person-centred to meet the needs of diverse populations across the North Coast region
Explore how ACP design could be improved for different population groups
Directly engage with priority populations and representative organisations to raise awareness and provide further resources specific to that cohort.
System
Ensure there are streamlined pathways and clear communication between healthcare providers, patients and families. This is essential to ensure continuity of care and improve patient and family experience
Continue to update HealthPathways so general practitioners can better identify services that would benefit palliative patients
Strengthen the role of telehealth and virtual care in palliative care to improve access to specialist consultations and after-hours GP services
Enhance understanding of My Health Record and promote the integration of up-to-date documentation to support coordinated, high-quality care
Sector
Stay across findings from the national evaluation (undertaken by Scyne Advisory) of the GCfAHPC program and adopt learnings where appropriate. The baseline report was released in March 2025, and the midpoint report released in June 2025

These opportunities have been considered in the context of previous initiatives undertaken and the following actions are listed below in Table 2.

Table 2: Impact of existing/ongoing activities

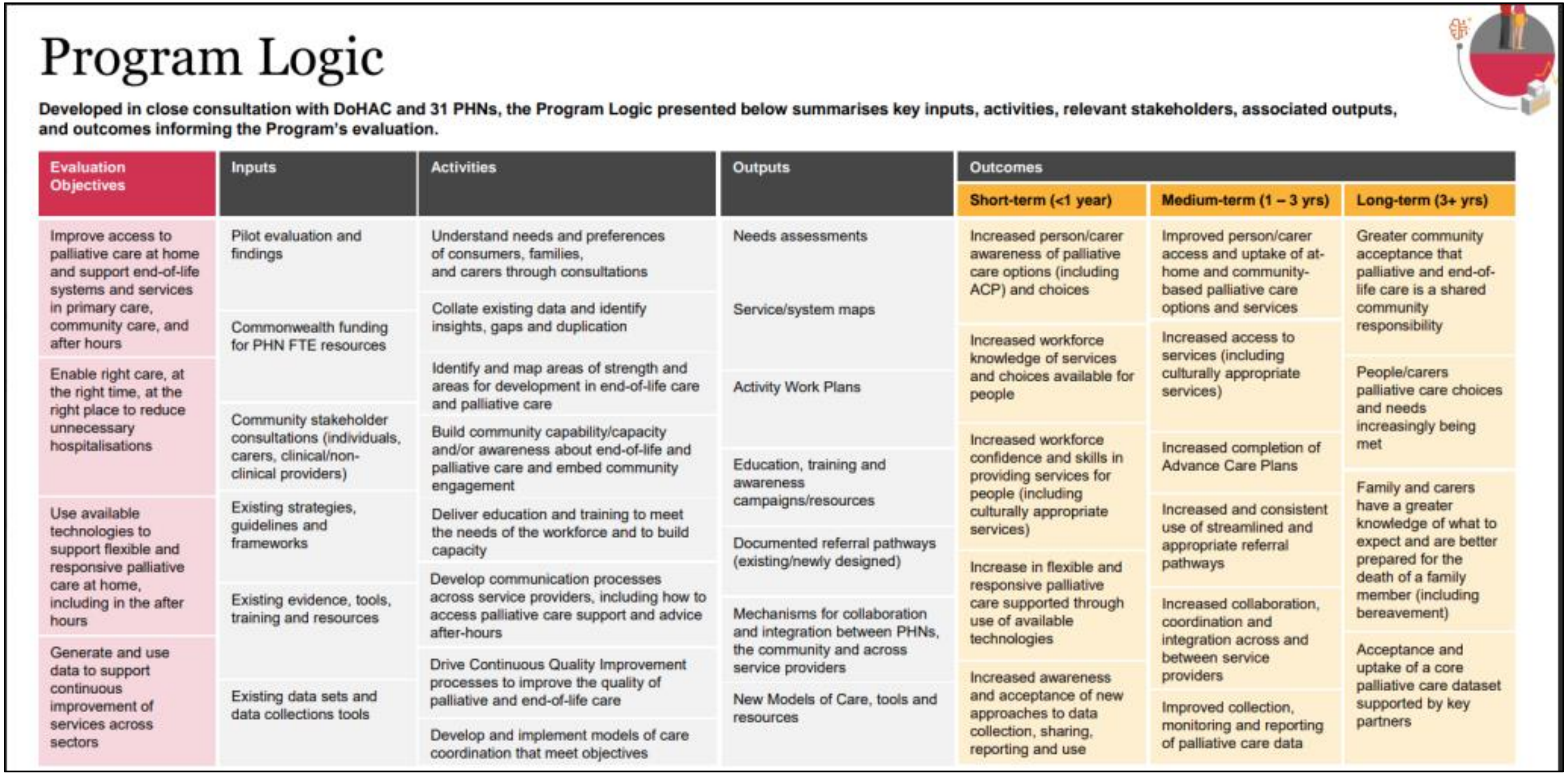
Needs assessment insight	Program stream	Action to take	HNC GCfAHPC initiatives
Awareness of palliative care is variable; one-off education improves knowledge but does not reliably lead to planning or behaviour change.	Community awareness & readiness	*Change:* Shift from broad, one-off sessions to targeted, place-based community education focused on readiness and planning over time.	Place-based community education series (Grafton & Kempsey). ACP/ACD embedded across all community education activities

GPs and aged care providers report variable confidence in early identification, ACP and managing deterioration at home. Practical, locally relevant education has greatest impact.	Workforce capability	*Continue:* Maintain workforce education as a core pillar, with increased focus on end-of-life readiness. *Start:* Increase awareness and coordination of providers to respond to the new Support at Home: End-of-Life Pathway.	GP Generalist Palliative Care Capacity Building Aged care workforce education and in-reach education, GP champions.
Fragmentation, unclear roles and poor coordination contribute to crisis-driven care and avoidable hospital presentations.	System integration & coordination	*Continue:* Strengthen coordination and shared understanding of roles across primary care, aged care and specialist palliative care.	End-of-Life Pathway implementation support ACP systems integration and pathway alignment. Communities of Practice and cross-sector engagement

9. Appendix 1 – GCfAHPC program logic

The GCfAHPC program logic shown below was developed by Scyne Advisory for the evaluation of the program.

The baseline report was released in March 2025



Program Logic

Developed in close consultation with DoHAC and 31 PHNs, the Program Logic presented below summarises key inputs, activities, relevant stakeholders, associated outputs, and outcomes informing the Program's evaluation.

Evaluation Objectives	Inputs	Activities	Outputs	Outcomes		
				Short-term (<1 year)	Medium-term (1 – 3 yrs)	Long-term (3+ yrs)
Improve access to palliative care at home and support end-of-life systems and services in primary care, community care, and after hours	Pilot evaluation and findings	Understand needs and preferences of consumers, families, and carers through consultations	Needs assessments	Increased person/carer awareness of palliative care options (including ACP) and choices	Improved person/carer access and uptake of at-home and community-based palliative care options and services	Greater community acceptance that palliative and end-of-life care is a shared community responsibility
	Commonwealth funding for PHN FTE resources	Collate existing data and identify insights, gaps and duplication	Service/system maps	Increased workforce knowledge of services and choices available for people	Increased access to services (including culturally appropriate services)	
Enable right care, at the right time, at the right place to reduce unnecessary hospitalisations		Identify and map areas of strength and areas for development in end-of-life care and palliative care	Activity Work Plans			People/carers palliative care choices and needs increasingly being met
	Community stakeholder consultations (individuals, carers, clinical/non-clinical providers)	Build community capability/capacity and/or awareness about end-of-life and palliative care and embed community engagement	Education, training and awareness campaigns/resources	Increased workforce confidence and skills in providing services for people (including culturally appropriate services)	Increased completion of Advance Care Plans	
Use available technologies to support flexible and responsive palliative care at home, including in the after hours	Existing strategies, guidelines and frameworks	Deliver education and training to meet the needs of the workforce and to build capacity	Documented referral pathways (existing/newly designed)		Increased and consistent use of streamlined and appropriate referral pathways	Family and carers have a greater knowledge of what to expect and are better prepared for the death of a family member (including bereavement)
	Existing evidence, tools, training and resources	Develop communication processes across service providers, including how to access palliative care support and advice after-hours	Mechanisms for collaboration and integration between PHNs, the community and across service providers	Increase in flexible and responsive palliative care supported through use of available technologies	Increased collaboration, coordination and integration across and between service providers	
Generate and use data to support continuous improvement of services across sectors	Existing data sets and data collections tools	Drive Continuous Quality Improvement processes to improve the quality of palliative and end-of-life care	New Models of Care, tools and resources	Increased awareness and acceptance of new approaches to data collection, sharing, reporting and use	Improved collection, monitoring and reporting of palliative care data	Acceptance and uptake of a core palliative care dataset supported by key partners
		Develop and implement models of care coordination that meet objectives				

10. References

ABS. (2021). Retrieved from https://tablebuilder.abs.gov.au/webapi/jsf/tableView/tableView.xhtml

ABS. (2021). *ABS search data*. Retrieved from https://www.abs.gov.au/census/find-census-data/search-by-area

ABS. (2021). *Search Census data: Community profiles by LGA*. Retrieved from https://www.abs.gov.au/census/find-census-data/search-by-area

ABS. (2021). *Search Cenus data: Community profiles by LGA*. Retrieved from https://www.abs.gov.au/census/find-census-data/search-by-area

Advance Care Planning Australia. (2025). *Advance care planning prevalance in Australia 2025*. Retrieved from https://www.advancecareplanning.org.au/?gad_source=1&gad_campaignid=17075956077&gbraid=0AAAAAoID8YrFxTGOh-DTaos7Ud2jgc2Mq&gclid=EAIaIQobChMIuc2hiLW2jwMVBKhmAh2jygDSEAAYASAAEgJE0_D_BwE

Advance Care Planning Australia. (2025). *What is advance care planning?* Retrieved from https://www.advancecareplanning.org.au/understand-advance-care-planning/what-is-advance-care-planning

Advanced Care Planning Australia. (2025). *Advanced Care Planning Australia*. Retrieved from https://www.advancecareplanning.org.au/__data/assets/pdf_file/0030/412788/Advance-Care-Planning-Prevalence-in-Australia-Report.pdf

Aged Care Quality and Safety Commission. (2021). *Outcome 5.7: Palliative care and end-of-life care*. Retrieved from https://www.agedcarequality.gov.au/strengthened-quality-standards/clinical-care/palliative-care-and-end-life-care

Aged Care Research & Industry Innovation Australia. (2025). *AI-Powered Palliative Care Assessment Tool (PCAT) for Aged Care Workforce Support*. Retrieved from https://www.ariia.org.au/aged-care-collaborative/accelerator-grants/ai-powered-palliative-care-assessment-tool-pcat

AIHW. (2016). *Australian Institute of Health and Welfare. (2016). 6.18 End-of-life care. In AIHW (Ed.), Australia's health 2016*. Retrieved from https://www.aihw.gov.au/getmedia/68ed1246-886e-43ff-af35-d52db9a9600c/ah16-6-18-end-of-life-care.pdf.aspx

AIHW. (2021). *Chronic condition multimorbidity 2021*. Retrieved from https://www.aihw.gov.au/reports/chronic-disease/chronic-condition-multimorbidity-2021/contents/what-is-multimorbidity-and-how-common-is-it

AIHW. (2024). *Chronic conditions*. Retrieved from https://www.aihw.gov.au/reports/australias-health/chronic-conditions

AIHW. (2024). *Older Australians*. Retrieved from https://www.aihw.gov.au/reports/older-people/older-australians/contents/health/health-disability-status

AIHW. (2025). *Palliative care services in Australia*. Retrieved from https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/data

Aoun, S. (2025, August 19). *Reframing palliative care: A call to action for a Compassionate Communities approach*. Retrieved from Caresearch: https://www.caresearch.com.au/About-Us/Newsroom/Palliative-Perspectives/Palliative-Perspectives-Blog-Details/ArtMID/17907/ArticleID/5886/Reframing-palliative-care-A-call-to-action-for-a-Compassionate-Communities-approach

Aoun, S. M., Abel, J., Rumbold, B., Cross, K., Moore, J., Skeers, P., & Deliens, L. (2020). The Compassionate Communities Connectors model for end-of-life care: a community and health service partnership in Western Australia. *Palliative Care and Social Practice*.

Aoun, S. M., Bear, N., & Rumbold, B. (2023). The compassionate communities connectors program: effect on healthcare usage. *Palliative Care and Social Practice*.

Aoun, S. M., Richmond, R., Rumbold, B., Gunton, K., & Noonan, K. (2022). ‘The more you give, the better it is for you. You know the reward is greater than the effort’: the Compassionate Communities Connectors’ experience. *Palliative care and social practice*.

APHRA. (2025). *New standard to enable registered nurse prescribing*. Retrieved from https://www.ahpra.gov.au/News/2025-05-30-RNs-poised-to-prescribe-in-major-leap-for-healthcare-access-and-delivery.aspx

Auon, S. M., Richmond, R., Rumbold, B., Gunton, K., & Noonan, K. (2022). The more you give, the better it is for yo. You know the reward is greater than the effort: the Compassionate Communities . *Palliative Care and Social Practice*.

Australian Government . (2023). *Support for informal carers*. Retrieved from https://www.pmc.gov.au/resources/draft-national-strategy-care-and-support-economy/goal-1-quality-care-and-support/support-for-informal-carers

Australian Government. (2021). Retrieved from https://www.agedcarequality.gov.au/providers/quality-standards/strengthened-aged-care-quality-standards

Australian Government. (2023). *Support for informal carers*. Retrieved from https://www.pmc.gov.au/resources/draft-national-strategy-care-and-support-economy/goal-1-quality-care-and-support/support-for-informal-carers

Australian Government Department of Health. (2019). *Exploratory Analysis of Barriers to Palliative Care Summary Policy Paper .*

Black, R., Hasson, F., Slater, P., & McIlfatrick, S. (2024). Building public engagement and access to palliative care and advance care planning: a qualitative study. *BMC Palliative Care*.

Borgstrom, E., Bashir, K., Pestano, C., & Ramsey-Jones, E. (2023). End of Life Doula UK Evaluation: Leeds and Surrounding Areas NHS Commission. *Open Research Online*. Retrieved from https://oro.open.ac.uk/91880/1/EoLDUK%20Leeds%20KTV%20report_oro.pdf

Boucher, J. E. (2020). Advance Care Planning: Having Goals-of-Care Conversations in Oncology Nursing. *Clin J Oncol Nurs*.

Davy, C., Harfield, S., McArthur, A., Munn, Z., & Brown, A. (2016). Access to primary health care services for Indigenous peoples: A framework synthesis. *International Journal for Equity in Health*.

Dementia Australia. (2025). *Dementia facts and figures*. Retrieved from https://www.dementia.org.au/about-dementia/dementia-facts-and-figures

Dementia Australia. (2025). *Dementia facts and figures*. Retrieved from https://www.dementia.org.au/about-dementia/dementia-facts-and-figures

Dening, K., Sampson, E., & Vries, K. (2019). Advance care planning in dementia: recommendations for healthcare professionals. *Palliative Care: Research and Treatment*.

DHDA. (2025). *Health Workforce Data*. Retrieved from https://hwd.health.gov.au/webapi/jsf/login.xhtml?invalidSession=true&reason=Session+not+established

Donnelly, N., Hickey, A, Burns, A., Murphy, P., & Doyle, F. (2015). Systematic Review and Meta-Analysis of the Impact of Carer Stress on Subsequent Institutionalisation of Community-Dwelling Older People. *Plos one*.

End of Life Doula UK. (2024). *Leeds NHS Commissioned Project*. Retrieved from https://eol-doula.uk/leeds-nhs-commissioned-project/

Grattan Institute. (2024). Retrieved from https://grattan.edu.au/report/dying-well/

Hava, C. (2025). *Bridging the palliative care education gpa for pharmacists*. Retrieved from https://www.australianpharmacist.com.au/bridging-the-palliative-care-education-gap-for-pharmacists/

LGBTQ+ Health Australia. (2025). *LGBTQ+ Palliative Care Project*. Retrieved from https://www.lgbtiqhealth.org.au/palliative_care

Noonan, K., Horsfall, D., Leonard, R., & Rosenberg, J. (2016). Developing death literacy. . *Progress In Palliative Care, Science and the Art of Caring*.

NSW Government. (2025, October). *Choose an enduring guardian*. Retrieved from https://www.nsw.gov.au/family-and-relationships/planning-for-end-of-life/choose-enduring-guardian

NSW Government. (2025). *Mid North Coast Local Health District*. Retrieved from https://mnclhd.health.nsw.gov.au/

NSW Government. (2025). *Northern NSW Local Health District*. Retrieved from https://nnswlhd.health.nsw.gov.au/

NSW Government Agency for Clinical Innovation. (2025). *End of Life and Palliative Care*. Retrieved from https://aci.health.nsw.gov.au/palliative-care/blueprint/intended-outcomes

NSW Health. (2019). *End of Life and Palliative Care Framework 2019-2024.* Retrieved from https://www.health.nsw.gov.au/palliativecare/Pages/eol-pc-framework.aspx

NSW Health. (2019). *End of Life and Palliative Care Framework 2019-204*. Retrieved from https://www.health.nsw.gov.au/palliativecare/Publications/eol-pc-framework.pdf

NSW Health. (2025). *Advance care planning*. Retrieved from https://www.health.nsw.gov.au/patients/acp/Pages/default.aspx

Palliative Care Australia . (2024). *National Palliative Care Week Lecture: The future of the care economy*. Retrieved from https://palliativecare.org.au/event/national-palliative-care-week-lecture-the-future-of-the-care-economy/

Palliative Care Australia. (2018). *Compassionate communities: An implementation guide for community approaches to end of life care.*

Palliative Care Australia. (2018). *Final Report: Compassionate Communities Feasibility Study.* Nous Group.

Palliative Care Australia. (2024). *Wellbeing in palliative care workforces - National Workforce Survey Findings Report 1*. Retrieved from https://palliativecare.org.au/statement/wellbeing-in-palliative-care-workforces-national-workforce-survey-findings-report-1/

Palliative Care Australia. (2024). *What is palliative care?* Retrieved from https://palliativecare.org.au/resource/what-is-palliative-care/

Palliative Care Australia. (2025). *Australia's palliative care workforce: Challenges and opportunities*. Retrieved from https://palliativecare.org.au/statement/australias-palliative-care-workforce-challenges-and-opportunities/

Palliative Care Australia. (2025). *National Palliative Care Standards*. Retrieved from Palliative Care Australia: https://palliativecare.org.au/national-palliative-care-standards/

Palliative Care Australia. (2025). *National Palliative Care Standards*. Retrieved from https://palliativecare.org.au/national-palliative-care-standards/

PATCAT. (2023). *Practice Aggregation Tool for the Clinical Audit Tool (PatCat).* Retrieved from Chronic disease in General Practice.

Pencs. (2025). *CAT Recipes*. Retrieved from https://help.pencs.com.au/display/CR/Palliative+Care+Recipes

Pencs. (2025). *CAT Recipes*. Retrieved from https://help.pencs.com.au/display/CR/Palliative+Care+Recipes

PHPCI. (2025). *Public Health Palliative Care International*. Retrieved from https://www.phpci.org/

Queensland Aboriginal & Torres Strait Islander Health Branch. (2015). Sad news, sorry business: guidelines for caring for Aboriginal and Torres Strait Islander people through death and dying. Brisbane: Queensland Health.

Queensland Government. (2025). *Specialist Palliative Rural Telehealth Service*. Retrieved from https://www.health.qld.gov.au/clinical-practice/referrals/statewide-specialist-services/palliative-rural-telehealth-service

Queensland Government. (2025). *Specialist Palliative Rural Telehealth Service*. Retrieved from https://www.health.qld.gov.au/clinical-practice/referrals/statewide-specialist-services/palliative-rural-telehealth-service

RACGP. (2019). *Advance care planning should be incorporated into routine general practice*. Retrieved from https://www.racgp.org.au/advocacy/position-statements/view-all-position-statements/clinical-and-practice-management/advance-care-planning

RACGP. (2019). *Polypharmacy*. Retrieved from https://www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/view-all-racgp-guidelines/silver-book/part-a/polypharmacy#ref-num-5

RACGP. (2023). *Advance care planning*. Retrieved from https://www.racgp.org.au/running-a-practice/practice-resources/practice-tools/advance-care-planning

Rao, V., Guyer, D., Almhanna, K., & Baum, L. (2021). Advance care planning, serious illness communication, and conversations to facilitate coping for patients with gastrointestinal malignancies: a narrative review. *Annals of Palliative Care Medicine*.

Rawlings, R., Miller-Lewis, L., & Swetenham, K. (2018). What role do Death Doulas play . *In Health &* , Vol. 27, Issue 3, pp. e82–.

Roberts, N. J., Harvey, L. A., Poulos, R. G., Ní Shé, E., Savage, I. D., Rafferty, G., & Ivers, R. (2022). Lesbian, gay, bisexual, transgender and gender diverse and queer (LGBTQ) community members' perspectives on palliative care in New South Wales (NSW), Australia. *Health and Social Care in the community*.

Scyne Advisory. (2025). *National Evaluation of the Greater Choice for At Home Palliative Care Program | Baseline report.* Retrieved from https://www.health.gov.au/sites/default/files/2025-09/evaluation-of-the-greater-choice-for-at-home-palliative-care-program-baseline-report-march-2025.pdf

Trivedi, N., Peterson, E., Ellis, E., Ferrer, R., Kent, E., & Chou, W. (2019). *Awareness of Palliative Care among a Nationally Representative Sample of U.S. Adults.* Journal of Palliative Medicine.

University of Wollongong. (2023). Retrieved from https://www.uow.edu.au/australasian-health-outcomes-consortium/pcoc/research-ethics-and-governance/research/national-palliative-care-coordination-project/

University of Wollongong. (2025). *National Palliative Care Coordination project*. Retrieved from https://www.uow.edu.au/australasian-health-outcomes-consortium/pcoc/research-ethics-and-governance/research/national-palliative-care-coordination-project/

van Gaans, D., Erny-Albrecht, K., & Tieman, J. (2022). Palliative Care Within the Primary Health Care Setting in Australia: A Scoping Review. *Public Health Review*.

Vitorino, J. V., Duarte, B. V., Ali, A. M., & Laranjeira, C. (2024). Compassionate engagement of communities in support of palliative and end-of-life care: challenges in post-pandemic era. *Frontiers in Medicine*.

Waldrop, D. P., & Meeker, M. A. (2012). Communication and advanced care planning in palliative and end-of-life care. *Nurse Outlook*.