Palliative and End-of-Life Care Needs Assessment

COORDINARE - South Eastern NSW PHN

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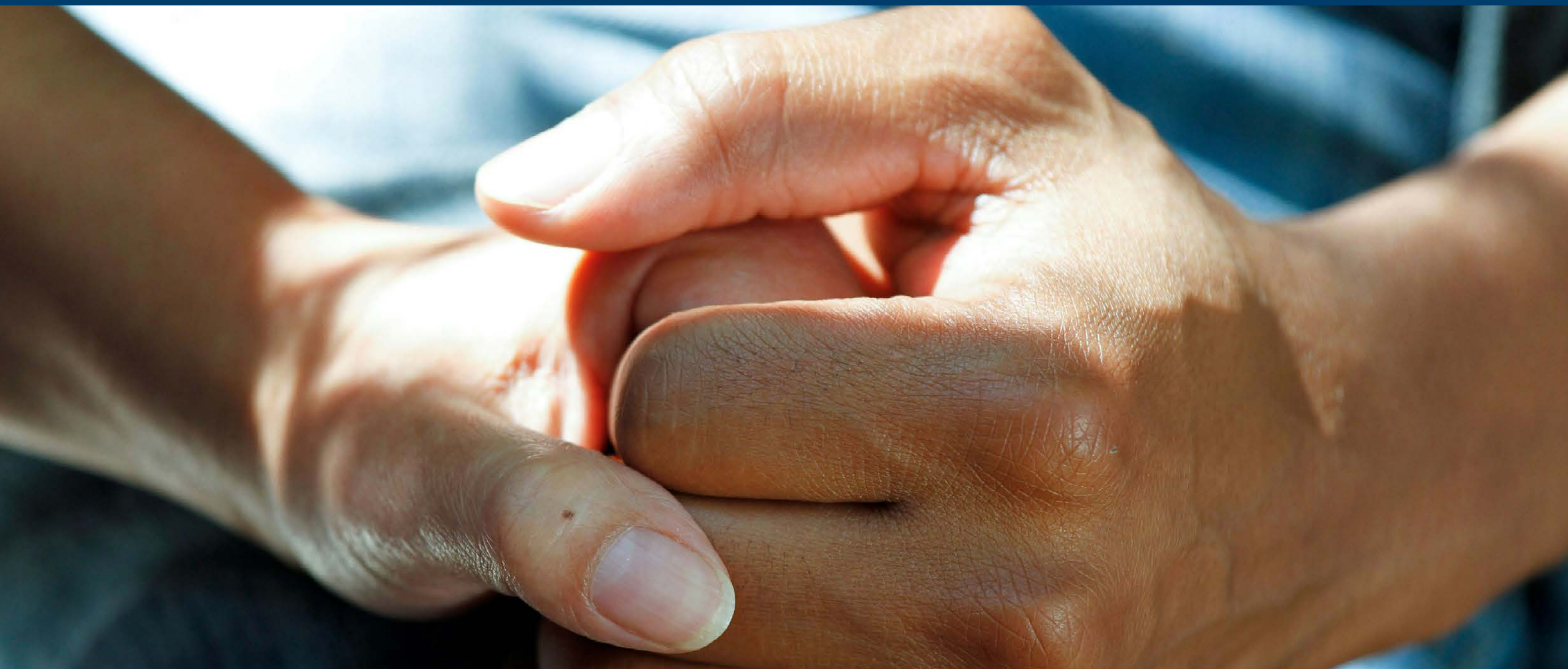
phn SOUTH EASTERN NSW

An Australian Government Initiative

Contents



Acknowledgements

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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.

Acknowledgement of Country

COORDINARE acknowledges the Traditional Owners and Custodians of the lands across which we live and work. We pay our respects to Elders past, present and emerging, and acknowledge Aboriginal and Torres Strait Islander peoples' continuing connection - both physical and spiritual - to land, sea and sky.

Warning

Aboriginal and Torres Strait Islander people should be warned that this document refers to the sensitive issue of death and dying.

Acknowledgement of program staff

This needs analysis was supported by the dedicated work of COORDINARE program staff, Jackie Caton and Julie Elliott whose expertise and commitment were integral to its development. Their coordination of stakeholder engagement activities, including consultations with community members and health professionals, enabled the collection of rich qualitative and quantitative data. The strong relationships established and maintained across the region were essential to building trust, supporting participation, and ensuring the analysis reflects local priorities, experiences, and service contexts.

Abbreviations

ABS	Australia Bureau Statistics
ACP	Advance Care Plan
AIHW	Australian Institute Health and Welfare
CAC	Community Advisory Committee
CALD	Culturally and Linguistically Diverse
GCfAHPC	Greater Choices for At Home Palliative Care
ISLHD	Illawarra Shoalhaven Local Health District
LGBTIQA+	Lesbian, Gay, Bisexual, Transgender, Queer Plus
GP	General Practitioner
PCOC	Palliative Care Outcomes Collaborative
PCOP	Palliative Care Outcomes Program
PHP	SENSWPHN Population Health Profile
PHN	Primary Health Network
RACH	Residential Aged Care Home
SENSW	South Eastern NSW
SNSWLHD	Southern NSW Local Health District

Executive summary

This Needs Assessment presents a comprehensive analysis of palliative and end-of-life care across South Eastern NSW (SENSW). Prepared by COORDINARE through the Australian Government funded Greater Choice for At Home Palliative Care (GCfAHPC) program, the assessment identifies current and emerging needs, service gaps, and priority actions to improve access to high-quality, coordinated, and culturally safe care between 2025 and 2029.

Context and demand

South Eastern NSW covers a large and diverse geographic area, with a significantly older population and higher-than-average rates of chronic and life-limiting illness. Demand for palliative and end-of-life care is increasing rapidly, driven by population ageing, multimorbidity, and socio-economic disadvantage in many communities. While most people wish to receive care and die at home, the majority continue to die in hospital or residential aged care, highlighting persistent misalignment between consumer preferences and system capability.

Service utilisation data show consistently higher rates of palliative-related hospitalisations for SENSW residents compared with NSW and national averages, particularly among people aged 75 years and over. This pattern suggests both high underlying need and ongoing gaps in timely access to community-based, coordinated palliative care, especially after hours and in rural and remote areas.

Methodology

The assessment uses a mixed methods approach, integrating quantitative data with extensive qualitative input. It draws on population health and epidemiological data, AIHW and PCOC datasets, program evaluations, and more than 400 stakeholder contributions from consumers, carers, clinicians, Aboriginal and multicultural organisations, aged care providers, Local Health Districts, and community services. Insights from GCfAHPC implementation since 2017 further strengthen the analysis.

Across the region, stakeholders consistently described a system that is committed but increasingly strained. Six interrelated areas of need were identified.

Key findings

Service access, navigation and coordination

Access to palliative and end-of-life care remains variable across the region. Fragmented referral pathways, inconsistent communication between providers, and poor transfer of care between hospitals, primary care, community services and aged care limit continuity and contribute to distress for consumers, carers and clinicians.

Workforce capacity

Workforce shortages across specialist palliative care, general practice and community nursing are compounded by variable skills, confidence and experience in end-of-life care. While the Illawarra Shoalhaven region has access to specialist led inpatient services, Southern NSW does not have equivalent on-site specialist coverage and instead relies more heavily on part-time remotely based specialists services, creating a clear disparity in service availability.

There is limited visibility of community/primary care workforce capacity and skills, and challenges in sustaining home-based care models, particularly in regional areas.

Consumer awareness and advance care planning

Low community death literacy, inconsistent and late uptake of advance care planning, and limited guidance for consumers and families result in missed opportunities for early and proactive conversations. Low community grief and bereavement literacy further affects preparedness and support for individuals and families.

Cultural safety

Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities continue to experience cultural, language and trust barriers. These challenges are exacerbated by limited culturally safe spaces, late engagement, insufficient workforce representation, and a lack of locally led, co-designed approaches.

Carer support

Carers are frequently unrecognised and under-supported, despite carrying significant emotional and practical responsibility. Gaps in education, navigation support, respite and bereavement care increase the risk of carer stress and burnout.

System and service integration

Poor integration across sectors, limited uptake of telehealth models, and under-use of enabling mechanisms such as Medicare Benefit Scheme (MBS) items reduce coordination and continuity of care. These system issues affect communication, care transitions and the ability of providers to deliver integrated, person-centred care.

Data and quality improvement

There is a poor shared understanding of available workforce data, capacity, service availability and outcomes across the region. Limited shared data and reporting restrict the ability to identify gaps, monitor performance and support continuous quality improvement. In addition, there is inconsistent utilisation of key national outcome / measurement frameworks such as the Palliative Care Outcomes Collaboration (PCOC) and the Palliative Aged Care Outcomes Program (PACOP). This inconsistency further limits the region's ability to track outcomes, benchmark services and build a cohesive understanding of system performance.

Strengths and opportunities

Despite these challenges, the region demonstrates strong foundations for improvement. Stakeholders expressed high levels of goodwill and readiness to collaborate. GCfAHPC investments have delivered tangible gains in workforce education, advance care planning, aged care support, volunteer services, cultural initiatives and system integration. These provide a solid platform for scaling effective models, strengthening partnerships, and embedding more consistent, person-centred care.

Priority directions 2025–2029

The Needs Assessment identifies clear priorities for action, including:

- improving service access, navigation and coordination, particularly for homebased and afterhours care
- strengthening workforce capability, sustainability and cultural competence
- raising consumer awareness while embedding advance care planning earlier and more consistently across the system
- co-designing culturally safe approaches with Aboriginal and culturally and linguistically diverse communities
- enhancing support for carers
- enhancing system and service integration, including care transitions, telehealth and better use of enabling mechanisms
- strengthening data, evaluation and continuous quality improvement.

Together, these priorities will guide COORDINARE’s planning and investment over the next three years and support collective action with partners to ensure people in South Eastern NSW can live well, and die with dignity, in the place of their choosing.

Introduction and background

Palliative care is integral to a coordinated and integrated health care system that can deliver care and services by placing the person at the centre of that care. The provision of support and care to meet the medical, physical, spiritual, and psychosocial needs of someone who has a life-limiting condition is a human right fundamental to health and dignity.

Palliative care is delivered in a variety of settings - hospital inpatient and outpatient services, specialist palliative care inpatient unit, community and primary health services, and increasingly in the person's home or another place of their choosing. Early engagement with advance care planning (ACP) empowers individuals, upholds their choices, and increases completion of their directives.

Demand for integrated palliative care is rising nationally, including across South Eastern NSW, driven by population ageing, multimorbidity, and chronic disease, while services remain fragmented and challenging to navigate, particularly for people wishing to receive care at home. Reported gaps in availability of palliative care in regional areas can leave people and their families without the support they need and reduces individual choice and preferences for care and place of death.

Recent Voluntary Assisted Dying (VAD) legislation has also introduced a requirement for patients considering VAD to have access to competent palliative care input. This has created an additional and immediate driver for more consistent, high quality palliative care capacity across the region.

Purpose and scope

This Needs Assessment examines the factors shaping palliative and end-of-life care in South Eastern NSW and highlights what people require to live well towards the end-of-life. Drawing on the experiences of consumers, carers and local service providers, it identifies opportunities to strengthen access to coordinated, high-quality and culturally appropriate support.

Many people continue to access palliative care late in their illness, often through hospital-based services. Referrals are frequently made well into the disease trajectory, despite strong evidence that early engagement with palliative care improves symptom control and helps avoid crisis-driven, futile or burdensome care. Strengthening primary care, after-hours support, local service coordination and clearer referral pathways will help people receive palliative care earlier and closer to home.

As end-of-life care is only one component of palliative care, enhancing community-based supports will ensure people benefit from symptom management and quality-of-life support throughout the full course of their illness.

These insights will guide COORDINARE's planning and investment over the next three years and inform our work with partners to strengthen palliative and end-of-life care across South Eastern NSW.

Methodology

This Needs Assessment uses a mixed-methods approach drawing on quantitative data and qualitative insights. It explored service accessibility, care transitions, workforce capacity, communication, advance care planning, cultural safety, and data and system improvement.

To build a comprehensive picture of need, the assessment integrates quantitative data with qualitative insights from consumers, carers, clinicians, and service providers. Data sources include:

- regional and national sociodemographic analysis
- bespoke population health data for SENSWPHN
- AIHW palliative care data
- findings from the ongoing independent review of the GCfAHPC in SENSW
- stakeholder consultations, community workshops, and surveys
- thematic analysis of advance care planning initiatives
- reviews of models of care and targeted reports on Aboriginal and CALD communities.

The assessment also draws on significant learnings from GCfAHPC work undertaken by COORDINARE – South Eastern NSW PHN since 2017, including model-of-care development, commissioned service evaluations, and insights from Clinical and Community Advisory Committees.

This mixed methods approach enables the assessment to:

- triangulate findings across diverse data sources
- combine lived experience with system-level evidence
- identify regional variation and equity impacts not apparent in single datasets.

Recent stakeholder engagement

Between September 2023 and November 2025, COORDINARE engaged more than 400 contributors, including:

- primary care providers
- community and residential aged care services
- NSW Health (LHDs and NSW Ambulance)
- volunteer organisations and peak bodies
- Aboriginal health organisations
- multicultural services
- national palliative care initiatives
- community members and carers.

Engagement activities included:

- semi-structured interviews (1:1 and small group)
- community workshops and forums
- online and paper-based surveys.

Demographics and population health profile

The South Eastern NSW Primary Health Network (SENSWPHN) covers a large and diverse region of more than 50,000 square kilometers. The catchment stretches from Helensburgh in the north to the Victorian border in the south, and inland to Snowy-Monaro, Queanbeyan, Yass and Goulburn.

Our region includes 11 local government areas and one territory, with around 680 towns, villages, and localities. It is home to one of the largest rural and regional populations in NSW.

Health services in the region are supported by two Local Health Districts (LHDs): Illawarra Shoalhaven LHD and Southern NSW LHD.

The SENSW region has a significantly older demographic, with more than 146,000 people aged 65 and over and strong projected growth in this age group, placing increasing pressure on local health and support services. The region experiences higher than both NSW and National average rates of chronic and life-limiting conditions, including coronary heart disease, dementia, cerebrovascular disease, lung cancer and COPD which are closely linked to ageing and drive greater need for palliative care. Compounding this, many older residents face socio-economic disadvantage, higher psychological distress, and social isolation, with a notable proportion living alone, all of which contribute to more complex care needs and underline the importance of accessible, coordinated palliative care across this large and diverse region.[1,2,3]

This Palliative and End-of-life Care Needs Assessment should be read in conjunction with a more detailed demographic, socio-economic and epidemiological profile of the SENSW catchment and is available as the Population Health Profile.[1]

Health Snapshot for South Eastern NSW PHN

Population

664,256
total population

22%
aged over 65 years

> 33,180 (5.2%)
people identify as Aboriginal and Torres Strait Islander

Region is home to **3.4%** of Australia's Aboriginal population, and **9.8%** of the total Aboriginal population in NSW

62,349 (9.7%)
culturally and linguistically diverse people

Top 3 non-English speaking countries of birth
1. India
2. North Macedonia
3. Italy

10.4%
non-English speaking at home

Top 3 non-English languages spoken at home
1. Macedonian
2. Italian
3. Arabic

15.6% projected population growth between 2021-2031

Health and related services

808 GPs
375 practice nurses

199 general practices

2 Local Health Districts (LHDs)

75 residential aged care facilities
63 home care services
134 home support outlets

22 public hospitals
16 emergency departments
30 community health centres

Social determinants

29% of the population experience high socio-economic disadvantage

Lower than NSW and Australian average for median weekly income for household, families and individuals in several areas of the region.

4.4% average unemployment rate

'health care and social assistance'

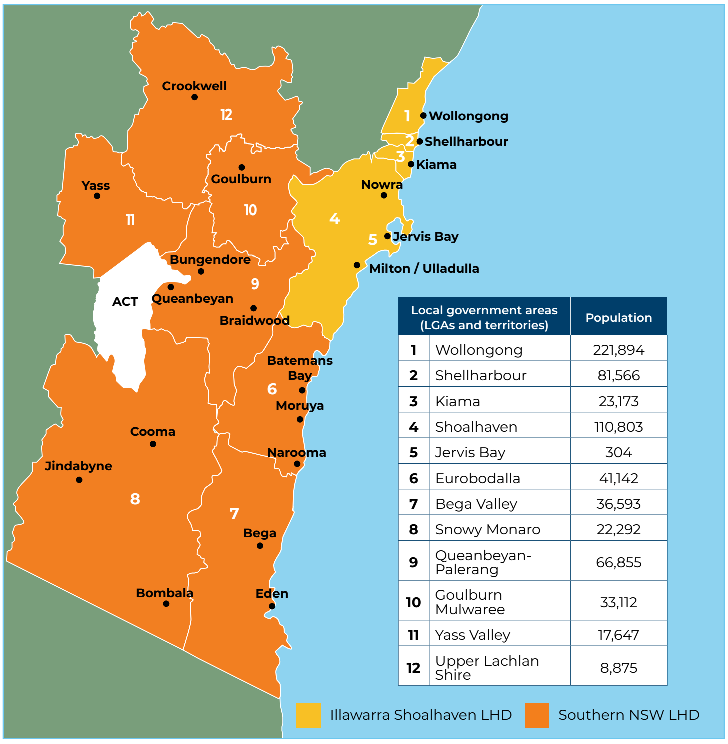
industry being the highest category for the employed population.

Social isolation - 10.9% of the resident population live alone

11.5% experiencing financial stress from rent or mortgage*

6.3% have no motor vehicle*

**of occupied private dwellings*



Local government areas (LGAs and territories)		Population
1	Wollongong	221,894
2	Shellharbour	81,566
3	Kiama	23,173
4	Shoalhaven	110,803
5	Jervis Bay	304
6	Eurobodalla	41,142
7	Bega Valley	36,593
8	Snowy Monaro	22,292
9	Queanbeyan-Palerang	66,855
10	Goulburn Mulwaree	33,112
11	Yass Valley	17,647
12	Upper Lachlan Shire	8,875

Chronic conditions

Top 5 causes of death in the region:

1. coronary heart disease
2. dementia (including alzheimer's)
3. cerebrovascular disease
4. lung cancer
5. chronic obstructive pulmonary disease

Aboriginal health

Poorer status on all social determinants of health:

- unemployment
- inadequate housing
- lower educational attainment
- vulnerability to childhood development risks
- poverty

Higher prevalence of most health and lifestyle risk factors and consequently a higher prevalence of most major long-term conditions.

Mental health and suicide prevention

Higher than NSW and Australian average estimates for:

- prevalence of long term mental or behavioural problems
- high or very high psychological distress

Higher than NSW and Australian rates for:

- suicide deaths
- intentional self-harm related hospitalisations

Alcohol and other drugs

Higher than NSW and Australian average prevalence figures for:

- high risk alcohol consumption
- smoking

South Eastern NSW PHN had the 4th highest age-standardised rates of alcohol attributable hospitalisation among all 10 PHNs in NSW, with rates among males being almost two times higher than females.

Source and citation: Ghosh, A. 2019, Population Health Profile: South Eastern NSW. COORDINARE - South Eastern NSW PHN. [Last updated: October 2025]

Palliative and end-of-life service demand

Demand for palliative care services will continue to increase across SENSW. Population growth is a key driver, with the highest growth projected for the 65 years and over age group projected to grow by 26.9% or 36,454 people by 2031.[1] This is further impacted by an increasing prevalence of coronary heart disease, dementia including Alzheimer's and cancer.

End-of-life care is provided in a range of settings, and whilst 70% Australians want to die at home only about 15% of people die at home despite their preferences, 50% of all deaths occur in a hospital and 30% occur in Residential aged care.[4]

There were 5,883 deaths recorded across the SENSW catchment in 2023. Overall, the SENSW region has higher than NSW state and Australian national rates of death from 'all causes' including most of the major causes of death.[1]

The major causes of death across the region from 2019-2023 are outlined in the table below (Table 1)[1].

Table 1: Major causes of death and their associated age-standardised death rates in SENSW, 2019-23

Top causes of death in SENSW PHN	Age-standardised death rate per 100,000 population		
	SENSWPHN	NSW	Australia
Dementia including Alzheimer's disease	46.3	43.2	43.5
Coronary heart disease	48.9	48.5	50.9
Cerebrovascular disease	29.7	29.3	27.5
Lung cancer	29.4	26.2	26.5
Chronic obstructive pulmonary disease	27.5	21.6	21.1
Diabetes	16.4	16.6	16.2
Colorectal cancer	16.9	16.3	16.1
Heart failure and complications and ill-defined heart disease	11.8	11	10.2
Prostate cancer	12	10	10.5
Cancer of unknown or ill-defined primary site	10.8	10.1	9.2
Pancreatic cancer	10.8	10.6	10.4
Cardiac arrhythmias	9.5	7.8	7.1
Coronavirus disease 2019	9.6	10.3	9.6
Breast cancer	10.6	10.1	9.9
Hypertensive disease	9	8.9	6.7
Suicide	14.1	11	12.4
Accidental falls	8.2	not in top causes for NSW	10.5
Influenza and pneumonia	7.5	7.1	7.6
Liver disease	8.9	not in top causes for NSW	not in top causes for Australia
Parkinson disease	6.9	not in top causes for NSW	not in top causes for Australia

Palliative care services provision and utilisation[5]

1. Medicare Benefits Schedule-based services

This refers to MBS-subsidised palliative medicine attendance and case conference services that are provided by palliative medicine physicians or specialists and are claimed under specialist palliative care MBS item numbers. In 2023-24, such services were provided to 464 people, who collectively received 1,214 services (Figure 1).

Figure 1: Crude numbers of MBS service provision in SENSW, 2023-24

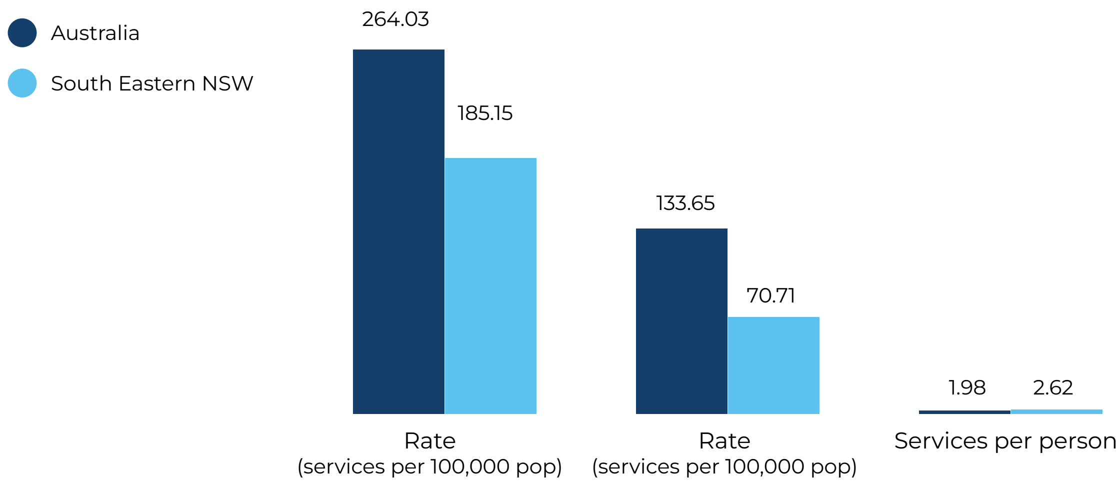
Number of people	Number of services
464	1,214

Within the SENSW catchment for 2023-24, people aged 75 years and over were the age cohort that received the most MBS-subsidised services (Figure 2).

Figure 2: Age distribution of MBS service utilisation in SENSW, 2023-24

While services per person were higher for SENSW residents, overall rates were lower than Australian national figures (Figure 3).

Figure 3: MBS service utilisation rate comparison of SENSW and Australia, 2023-24



2. Pharmaceutical Benefits Schedule-based services

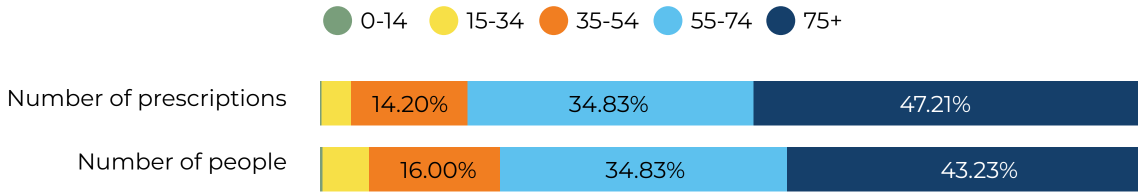
This refers to palliative care-related prescriptions that are defined as medications listed in the Palliative Care Schedule under the Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS). It is a count of medications dispensed, rather than a count of prescriptions written by clinicians. In 2023-24, 14,026 people received 45,432 prescriptions in the SENSW region (Figure 4).

Figure 4: Crude numbers of PBS service provision in SENSW, 2023-24

Number of people	Number of prescriptions
14,026	45,432

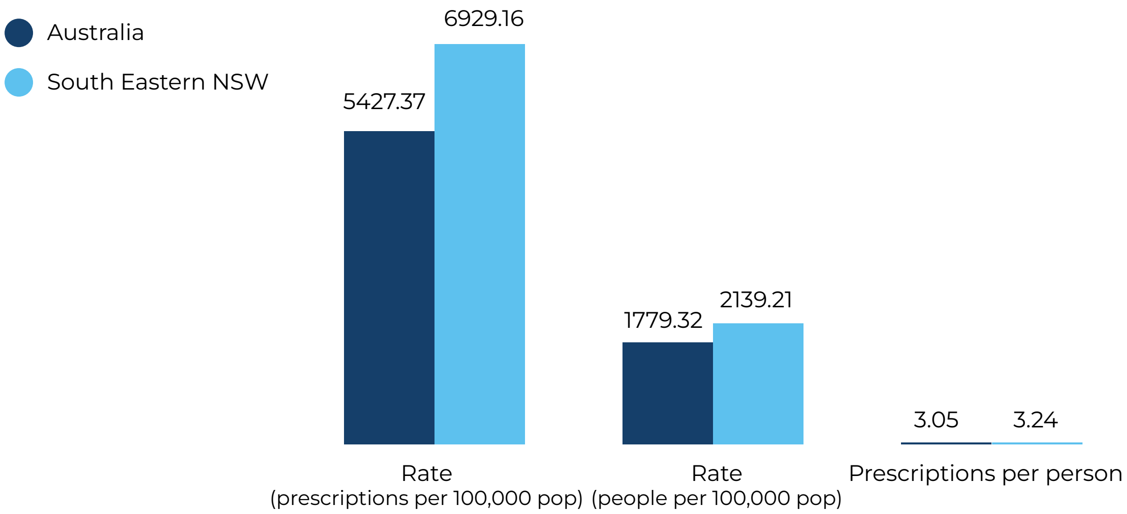
Within the SENSW catchment for 2023-24, people aged 75 years and over were the age cohort that received the most PBS prescriptions (Figure 5).

Figure 5: Age distribution of PBS service utilisation in SENSW, 2023-24



Prescriptions per person as well as the overall rates were higher for SENSW residents than Australian national figures (Figure 6).

Figure 6: PBS service utilisation rate comparison of SENSW and Australia, 2023-24



3. Hospital based services

Palliative care-related hospitalisation (admitted)

This refers to a hospitalisation where palliative care was a component of the admitted patient care provided during all or part of the episode. These hospitalisations can be divided into two groups: 1) primary palliative care hospitalisations with a recorded care type of palliative care, and 2) other palliative care hospitalisations with a recorded diagnosis of palliative care, but the care type is not recorded as palliative care. There were 3,093 primary palliative care hospitalisations in 2023-24 in the SENSW region (Figure 7).

Primary palliative care service event (non-admitted)

This refers to a non-admitted patient service event with a recorded care type of palliative care, where the primary clinical purpose or treatment goal is optimisation of the quality of life of a patient with an active and advanced life-limiting illness. These services are often associated with an emergency or admitted patient episode for which diagnostic or follow-up care is required without requiring hospital admission. There were 34,144 non-admitted primary palliative care service events in 2023-24 in the SENSW region (Figure 7).

Figure 7: Crude numbers of hospital-based service provision in SENSW, 2023-24

Admitted Patient Palliative care –
Number of hospitalisations

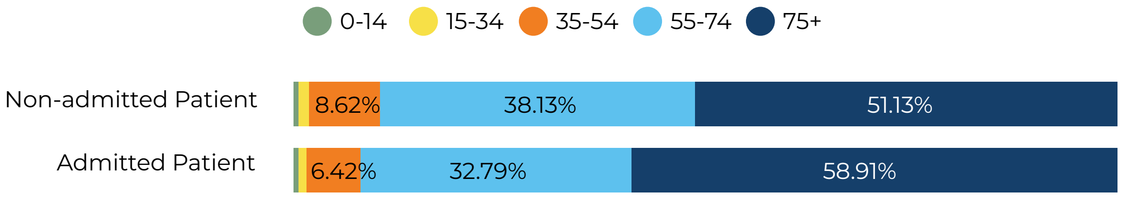
3,093

Non-admitted Patient
Primary Palliative care –
Number of service events

34,144

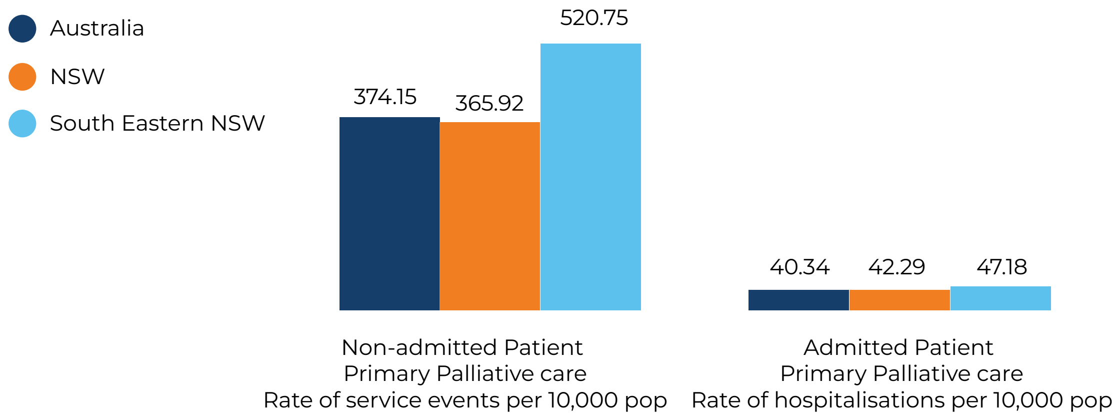
Within the SENSW catchment for 2023-24, people aged 75 years and over was the age cohort that received the most hospital-based service delivery (Figure 8).

Figure 8: Age distribution of hospital-based service utilisation in SENSW, 2023-24



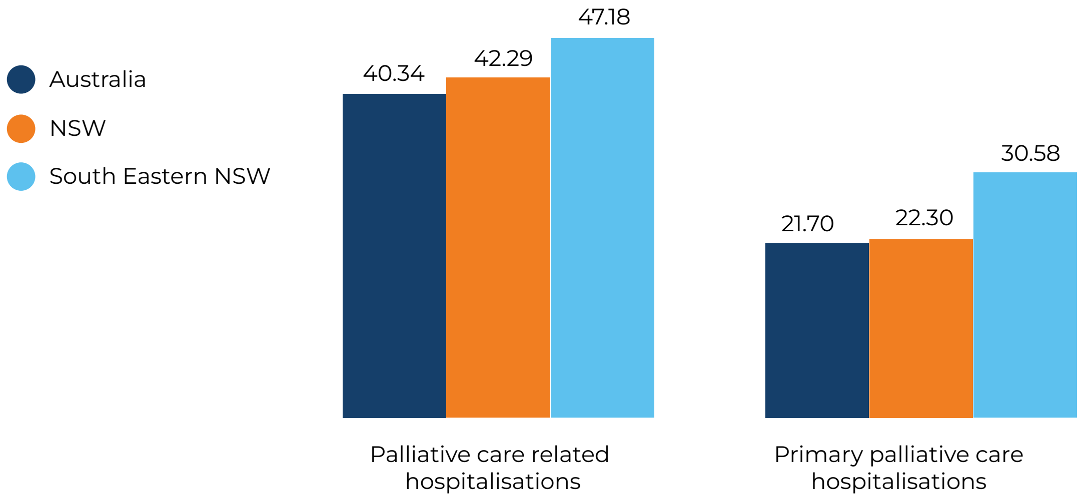
Service rates were higher for SENSW residents than Australian national figures as well as higher than NSW state rates (Figure 9).

Figure 9: Hospital-based service utilisation rate comparison by admission type of SENSW, NSW and Australia, 2023-24



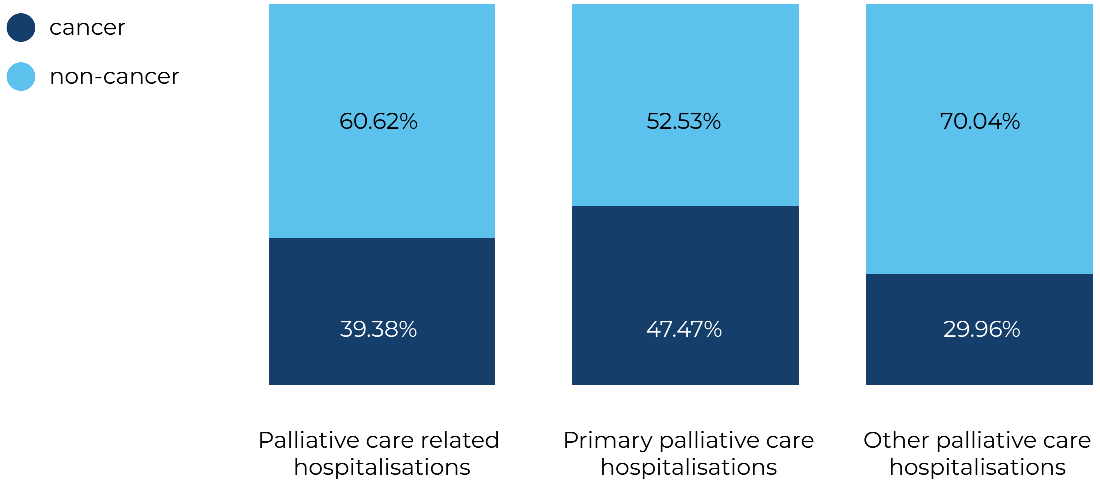
2023-24 rates for both all palliative care related hospitalisations as well as primary palliative care hospitalisations were higher for SENSW catchment residents compared to Australian national as well as NSW state overall figures (Figure 10).

Figure 10: Overall hospital-based service utilisation rate comparison of SENSW, NSW and Australia, 2023-24



It should be noted that both cancer-based diagnoses as well as other conditions contribute to palliative care hospitalisations, as seen in the figures below for SENSW in 2023-24 (Figure 11).

Figure 11: Hospital-based service provision distribution by diagnosis category of SENSW, 2023-24



While the 2023-24 hospitalisation rates for SENSW catchment residents is the highest it has ever been across all hospitalisation types rates, trends for all palliative care related hospitalisations as well as primary palliative care hospitalisations show rates for residents of SENSW are typically higher than the overall Australian national rates (Figure 12 and Figure 13).

Figure 12: Overall hospital-based service utilisation rate comparison of SENSW, NSW and Australia, Last 4 financial years

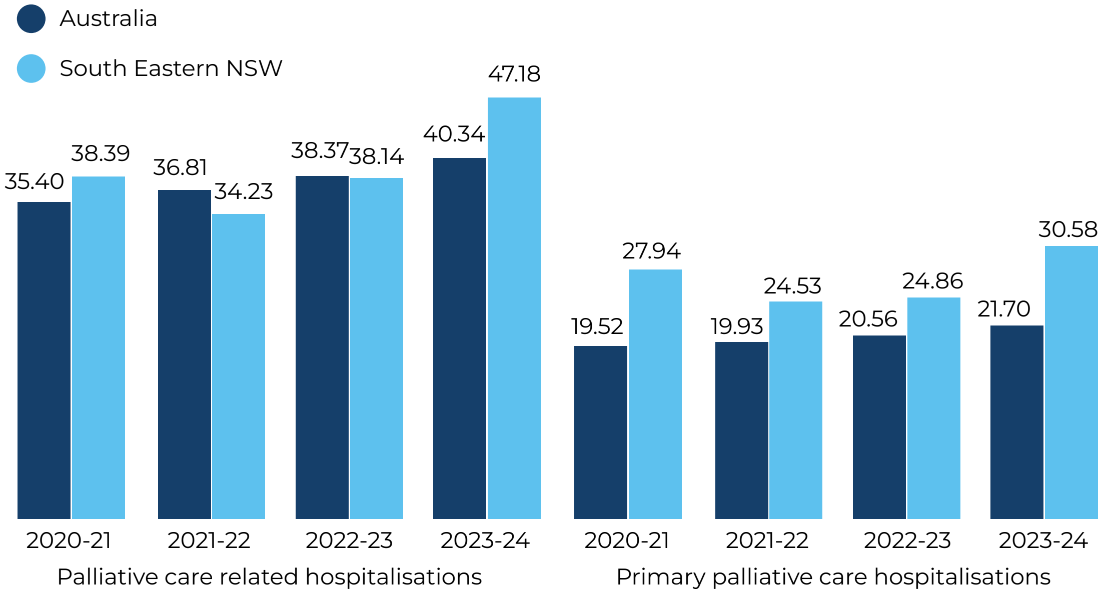
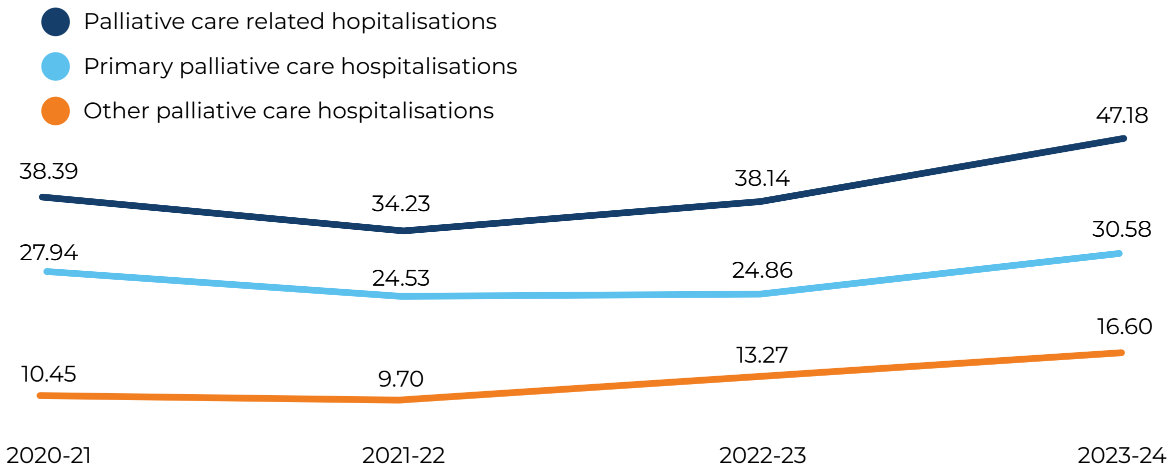


Figure 13: Overall hospital-based service utilisation rate trends of SENSW, Last 4 financial years



Relative service provision and utilisation insights[4]

A comparison of key palliative care utilisation metrics for 2023-24 was completed across all 31 PHN catchments in Australia. Figures for the SENSW catchment and associated ranking across PHNs nationally is shown below (Table 2).

Table 2: Key metric-based ranking of SENSW, 2023-24

Metric	Latest Year Figures	National Rank
Admitted Patient - Hospitalisation rate per 10,000	47.18	9
MBS-Rate of people per 100,000	70.71	10
MBS-Rate of services per 100,000	185.15	13
Non-Admitted Patient - Services rate per 10,000	520.75	5
PBS-Rate of people per 100,000	2,139.21	8
PBS-Rate of prescriptions per 100,000	6,929.16	10
Primary Palliative Care: Cancer - Hospitalisation rate per 10,000	13.11	13
Primary Palliative Care: Non-cancer - Hospitalisation rate per 10,000	17.47	7

Overall, these figures show that our region has higher than average use of hospital, outpatient and primary care services for palliative and chronic conditions, with particularly high demand for non-admitted care and palliative-related medications. The elevated rate of non-cancer palliative hospitalisations suggests that people with life-limiting illnesses other than cancer may not have clear or consistent pathways into palliative care, leading to later identification and more crisis-driven presentations. On balance, the data indicates a community with increasing complexity and symptom burden, and a strong reliance on hospital-based support, highlighting the importance of strengthening early, community-based and better-coordinated palliative care options across the region.

Workforce

The palliative care workforce encompasses a wide range of roles, including specialist palliative care clinicians, nurse practitioners, hospital-based nursing and community nursing teams, general practitioners, practice nurses, allied health professionals, aged care workers in both residential and community settings, Aboriginal and Torres Strait Islander health workers, interpreters, pastoral care workers, volunteers, support staff, and unpaid carers.

Across the region, workforce varies significantly. For example, while the Illawarra Shoalhaven has specialist inpatient palliative care services, specialist nursing staff and specialised allied health. In contrast, Southern NSW does not have equivalent onsite specialist coverage and instead relies more heavily on part-time remotely based specialist support. This creates notable differences in service availability, clinical presence and responsiveness across the broader region.

At present, detailed and reliable workforce data is not readily available at a regional or local level, limiting our ability to accurately quantify the size, distribution, and capacity of the palliative care workforce. This represents a significant data gap and highlights an opportunity for partners to work together on establishing clearer workforce mapping to support regional planning.

There is also greater ability to quantify hospital-based palliative care services, both inpatient and outpatient, whereas data on primary care, community-based services and aged care providers is far less readily available, limiting understanding of the true capacity, distribution and skill mix across community and primary care settings.

Palliative care service landscape

Primary care

Primary health care is the entry point of contact within the health system and plays a critical role in delivering palliative care through a range of professionals, including but not limited to general practitioners (GPs), nurses, Aboriginal health practitioners, social workers, allied health professionals, and pharmacists.

A person's palliative care journey is never linear and in SENSW there are several service providers, care pathways, and funding organisations within palliative care, and with varying eligibility criteria. Consultations noted elsewhere in this document showed that consumers and health practitioners all identified a desire for a more integrated care system.[6,7]

GPs in the region are central to palliative and end-of-life care due to their long-term relationships with patients. A small number of GPs see a high proportion of palliative care patients and therefore provide in-home care and care to residents in residential aged care. Consultations in the region identified a large variability in palliative care commitment, knowledge, and skill.[6,7,8,9]

> *"Palliative care is not our full-time job, it's only a very small part of our job; palliative care is one part of what we do generally."- GP*

Local Health Districts (LHDs) in SENSW

Illawarra Shoalhaven Local Health District (ISLHD) and Southern NSW Local Health District (SNSWLHD) deliver specialist palliative care across inpatient and community settings. The ISLHDs core services include inpatient wards, consultative services, community teams, symptom management clinics, grief and bereavement support, equipment loans, after-hours support, and compassionate volunteer assistance.

In the SNSWLHD specialist palliative care services are based in Queanbeyan, Goulburn, Eurobodalla, Cooma, and Bega Valley with outreach to all communities and after hours nurse phone support. These areas are characterised by outlying suburbs and small towns. Cooma and Upper Lachlan (serviced by Goulburn Base Hospital) have lower than average resident density per square kilometre. People who live in outlying areas will have greater distances to travel to receive services.[1]

Residential Aged Care Homes

Palliative care is also provided to residents living in Residential Aged Care Homes (RACH). Across the region, 75 RACH deliver community-based services. All residential aged care facilities in the Illawarra Shoalhaven have access to the NSW Health Aged Care Outreach Service (ACOS), which provides dedicated virtual and in-person clinical support to every facility across the Illawarra Shoalhaven Local Health District.

In addition to ACOS, SENSWPHN is committed to ensuring that staff who work after hours in RACH have access to education that builds confidence and skills in palliative care that will prevent unnecessary transfer to the emergency department (ED). An emerging service development is the establishment of an ACOS service by the SNSWLHD. This is expected to be in operation by mid-2026, with service reach being determined by the SNSWLHD project team.

Private palliative care services in SENSW

Palliative Aged Care Consultancy Service

This is a private nursing service which offers a wide range of services providing specialist nursing care through a multi-disciplinary team. The business provides a proactive, adjunct and timely intervention to optimise care for residents and works collaboratively with RACH staff, general practitioners and other palliative care services.

End-of-Life doulas

An End-of-Life Doula is a non-medical professional who provides emotional, spiritual, and practical support to people with a life-limiting illness and their families. Working alongside clinical teams, they offer companionship, comfort, and guidance from diagnosis through death and into early grief support. This is an emerging workforce in our local area, and further work is required to understand not only the scope of their role, but also the size of the workforce and the ways in which End-of-Life Doulas connect and collaborate with other service providers.

Palliative care outcomes

Understanding palliative care needs in South Eastern NSW depends on consistent, standardised outcomes data. National frameworks like PCOC and PACOP play an essential role in providing this information.

PCOC supports palliative care providers to measure the impact of care on people with life-limiting illness, embedding routine standardised assessments and enabling benchmarking at local, state and national levels. PACOP provides an equivalent framework for residential aged care, using structured assessments and a nationally consistent outcomes collection to identify changing care needs, support timely responses, and monitor service performance through regular reporting and benchmarking.

Several local providers across the region are involved in the initiative. Participating services collect data through routine clinical assessments that apply standardised language, enabling meaningful benchmarking and quality improvement. However, inconsistent utilisation of key national outcome / measurement frameworks such as the PCOC and the PACOP. This inconsistency further limits the region's ability to track outcomes, benchmark services and build a cohesive understanding of system performance.

Strengthening and standardising the use of PCOC and PACOP across the region would create a consistent, reliable data foundation that improves outcome tracking, supports better benchmarking and enables more coordinated, equitable palliative care planning.

Summary of work undertaken

Program activities delivered since 2022 under Greater Choice for At Home Palliative Care were structured around four key focus areas, supported by a range of targeted initiatives. These focus areas included:

- **Workforce capacity and capability**
  - educational webinars, cultural workshops and GP specialist team mentoring and training opportunities
  - launched a self-paced online learning page
  - completed a Model of Care review and developed a localised electronic Palliative and End-of-life Care Framework
  - developed and implemented an Advanced Care Planning (ACP) Quality Improvement Toolkit for use by general practice.
- **Systems and service integration**
  - facilitated the review and monitoring of the Palliative and End-of-life care pathway suit for the HealthPathways sites
  - streamlined referral process in partnership with LHDs
  - systems review of Palliative and End-of-life Care for Aboriginal communities.
- **Consumer awareness**
  - Last Days Carer workshops
  - Seniors Week and Live the Life You Please events across three regions
  - dissemination of advance care planning information packs.
- **Data and quality improvement**
  - developed an implement ACP toolkit
  - implemented After Death Audit and Death Literacy Index.

Outcomes from Greater Choice for At Home Palliative Care

Over 1,195 people attended a range of workshops and events and received advice and resources on advance care planning. Participants who attended advance care planning workshops reported increased confidence and awareness about end-of-life planning and advanced care. The cultural competency workshop was well-received by 15 participants and highlighted the need for ongoing education on cultural and spiritual aspects of care for Aboriginal and Torres Strait Islander peoples.

Challenges in program delivery

- Barriers included the time-consuming nature of implementing After Death Audits in general practice, slow uptake of the advance care planning toolkit
- Integration of advance care planning in all care planning practices
- Consistent use of terminology between services
- The lack of MBS payments for activities such as travel to undertake home visits
- Clarity on when and how to refer to palliative care, including the creation of templates to streamline this process and the processes around transfer of care between providers
- Ongoing workforce shortages in aged care, primary and allied health
- Community home care providers and aged care assessment services are underutilised and are well placed to engage in effective conversations or answer questions of consumers
- More information regarding planning for end.

Stakeholder engagement and consultation findings

The qualitative data from stakeholder and community consultations are organised into five key themes and indicate several challenges for consideration regarding palliative care and end-of-life services in SENSW.

Overall, the consultation findings describe a system that is committed but both constrained and challenged by rising demand, workforce shortages, fragmented coordination, and limited cultural readiness. Consumers, carers, and communities identified a desire for palliative and end-of-life care support and services that are consistent, accessible, culturally safe, and locally responsive. Strengthening death literacy across communities and the workforce was seen as an important enabler of this, helping people navigate choices with confidence and supporting more coordinated care. The local healthcare workforce is willing but requires better support, structured pathways, and sustainable resourcing.[6,7,8,9,10,11]

Access and equity

Access to palliative and end-of-life care across South Eastern NSW is variable, with marked differences between metropolitan, rural and remote communities, limited specialist palliative care inpatient unit facilities, and restricted access to after hours support. Priority populations such as frail older people, people living with dementia or intellectual disabilities, Aboriginal, multicultural and LGBTQIA+ communities continue to face additional cultural, language and trust barriers, highlighting the need for inclusive and culturally safe practice across all services.[1,2,6,7,11]

Growing demand, driven by chronic disease and an ageing population, is occurring alongside low awareness and inconsistent use by health professionals of existing models of care. These issues make it difficult for people to navigate and access services and receive timely support. Access to services in smaller regional areas, particularly in Southern NSW are hindered by a lack of, or in some locations, an absence of access to public transport. Cross-border arrangements between the ACT and Southern NSW further disrupt continuity of care for many communities with limited local options.[1,2,6,7,11]

> ***"You're travelling with a man who feels like his head is being sloshed around in a bucket, I had him wedged into a pillow, I'm dragging him out of bed Monday morning, sticking him in a car, taking him up to Canberra, dragging him into a motel, dragging him in and out of hospital for five days and then taking him home." - Carer***

Workforce capacity and capability

There is a shortage of access to specialist palliative care clinicians particularly in Southern NSW and trained GPs across the region, with succession planning and workforce replenishment emerging as critical issues. Workforce skills and confidence in initiating conversations and responding to changing consumer needs are inconsistent, and providers report significant emotional burden and burnout.[8,9] In addition, gaps in cultural competency and inclusive practice persist, particularly in supporting Aboriginal peoples, culturally and linguistically diverse communities, and LGBTQIA+ individuals.[12,13]

General practitioners play a vital role but face significant barriers. The MBS model does not specifically fund the travel or provide adequate remuneration for home visits, palliative case conferencing, and extended conversations required in palliative care. Awareness and utilisation of alternative times is not well recognised. Time pressures, variable interest, and limited integration across services affect GP capacity to provide home-based care.[6,7]

> ***"LHD nurses are remunerated for their travel, home visits etc. however with the lack of MBS items available for home visits and palliative care, the GP is out of pocket for travel and after hours visits." - GP***

> ***"Palliative care is time consuming and to be done well requires access to allied health and increased monitoring that palliative care service provides. If a patient is referred and is then found to be stable and not requiring complex input, we can discharge them back to care of GP - but do not want to give GPs the impression they should be shouldering the responsibility of coordinating end-of-life care single-handedly."- Specialist Palliative Care team member***

Communication and referral pathways

Fragmented communication and unclear referral pathways continue to hinder coordinated palliative and end-of-life care. Referral processes vary between acute, primary and community settings, and information sharing between providers is often inconsistent, which makes it difficult for teams to work together effectively. Roles and responsibilities across services are not always well understood, and the use of assessment tools and terminology differs across organisations. These issues are compounded by limited integration between primary care, Local Health District services, volunteers and community providers, resulting in gaps in planning, commissioning and continuity of care.[6,7,12]

> ***“Sometimes I feel like I don’t have much control once I’ve referred to palliative care, this is due to lack of communication and correspondence.” - GP***

> ***“In my practice, communication occurs via informal pathways as I can’t rely on traditional methods. It can be weeks or months before I receive correspondence, and often my patient has already died.” - GP***

> ***“We are on the ground, and it feels like our information is not valued by palliative care and others.” - Home care service provider***

Cultural safety and responsiveness

Aboriginal and Torres Straight Island and culturally and linguistically diverse communities continue to face significant barriers to equitable palliative and end-of-life care, with cultural needs often overlooked and limited access to appropriate liaison support. Aboriginal people frequently present later in the palliative stage due to mistrust of the health system, cultural taboos and a lack of culturally safe spaces, along with inconsistent involvement of Aboriginal liaison staff.[7,12] CALD communities have trouble engaging in advance care planning discussions because of cultural beliefs, misunderstandings about palliative care and language challenges.[7] These issues are also evident for other priority populations, including LGBTQIA+ people, individuals with intellectual disabilities, children, frail older people and those living with dementia, all of whom require inclusive care pathways and dedicated staff training to support culturally safe and person-centred practice.

> ***“A lack of awareness and understanding of palliative care is a common barrier for Aboriginal peoples in accessing palliative care. This can include understanding what it is, how it could help, what services and supports are available.” - Snr Aboriginal Health Worker***

> ***“For some people, cultural and spiritual needs may be more important than meeting physical needs.” - Aboriginal Health Worker***

> ***"Within CALD communities, there is a hesitancy to visit a GP to discuss advance care planning due to the taboo nature of discussing death and dying." - Provider***

> ***"Past experiences or losses may lead to unexpected and emotional outcomes when discussing death and dying" - Provider***

Consumer awareness and carer support

Consumers continue to experience low levels of health, death and grief literacy, which contributes to fear, mistrust and ongoing misconceptions about palliative care as an end-of-life treatment only. Limited awareness and uptake of advance care planning leads to late referrals and reduces opportunities for early, person-centred planning. Although many people prefer to remain at home, this places significant emotional and practical pressure on carers, who often do not recognise themselves in the caring role and are not identified early by services. Carers frequently lack access to clear information, navigation support, education, respite and bereavement services, which increases their risk of stress and burnout.[6,7,10]

> ***"The workshops gave me the opportunity to view this information from the perspective of my clients in the community and reflect on how I can use this to assist them in forward planning." - Consumer attending '10 Things to Know Before You Go'***

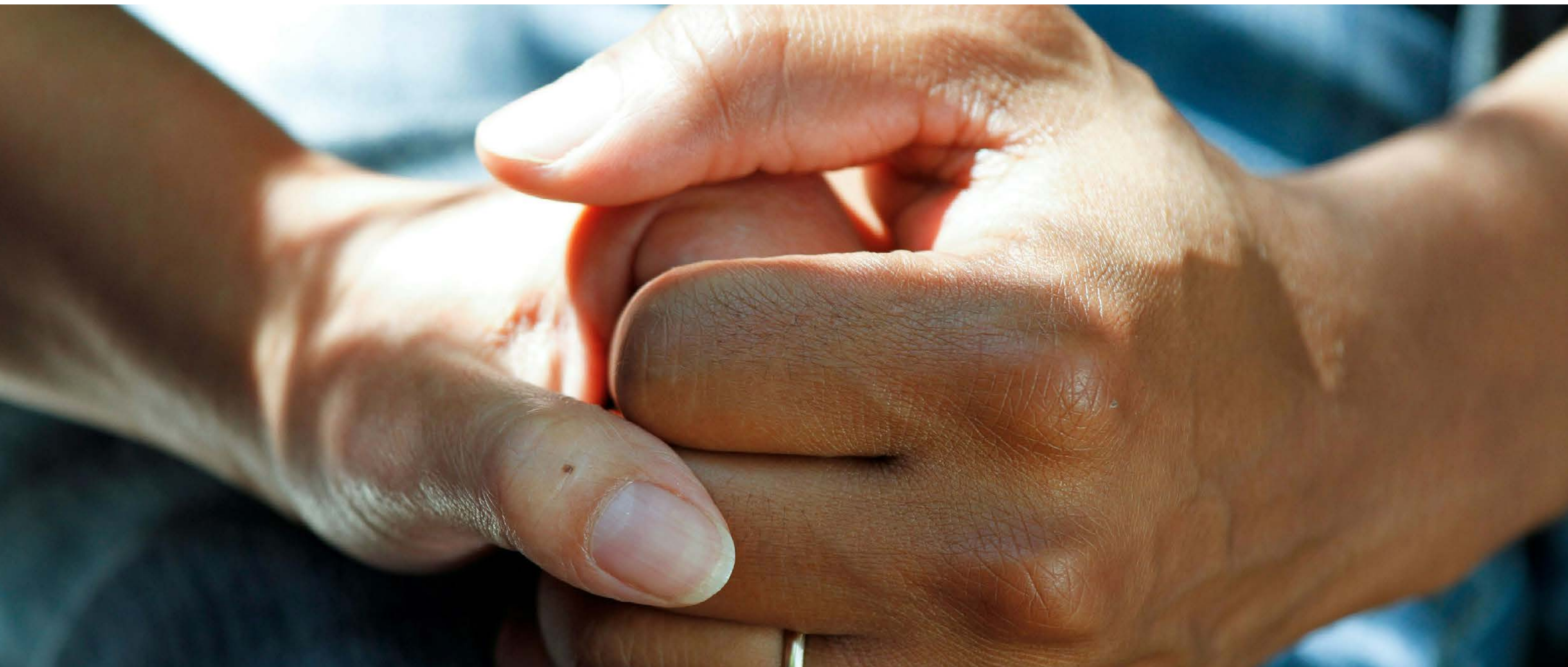
> ***"I am taking these handouts home to talk to my family. We need to talk and plan!" - Consumer attending '10 Things to Know Before You Go'***

Persistent challenges identified

- Short-term funding cycles limit sustainability
- Limited Aboriginal workforce representation and cultural responsiveness
- Workforce gaps in cultural competence and trauma-informed care
- Emotional strain on providers and constrained consumer engagement due to fear, cultural taboos and misconceptions
- Inconsistency with early intervention and diagnosis of deteriorating persons residing in Residential Aged Care, including recipients of home care services
- Aged care workforce is facing significant challenges, including workforce shortages, high turnover and difficulties in attracting and retaining staff particularly in rural and regional areas.

Local strengths and opportunities

- Strong stakeholder relationships across the region
- Strong stakeholder commitment and goodwill to improve access to palliative and end-of-life care across the region
- Examples of good practice include:
  - whole-of-practice approaches
  - effective mentoring and integration of clinical tools into software
  - established relationships across organisations with community palliative care teams
- Shared programs, education resources, and templates offer opportunities for adaptation and scaling across the region
- Aged care workforce and service providers are committed to providing palliative care to residents
- Palliative care, wound care and identifying deterioration of residents and have been the focus of on-going capacity building of RACH staff particularly after hours.



Key areas for action

Key findings showed opportunities for collaborative engagement to continue improvement in the delivery of GCfAHPC. The table below outlines potential options for consideration, aligning priority areas for action with documented needs and practical opportunities identified. These options are not exhaustive and are intended to inform discussion, planning and future decision making.

Key area for action	Alignment to documented need	Opportunities for consideration
1. Service access, navigation and coordination	a. Large ageing population driving demand for palliative and end-of-life care b. Variable access to services c. Fragmented referral pathways, poor care coordination and disjointed information sharing across providers d. Inconsistent communication between providers e. Poor transfer of care between hospitals, primary care, community services and aged care f. After hours support inconsistent, especially in regional areas g. Limited specialist palliative care inpatient and respite services in Southern NSW	• Advocate for GP involvement and after hours service expansion • Embed holistic in-home assessments and leverage volunteer networks • Explore models that enable people to remain at home where there is a preference including outreach and better use of telehealth with the right training, equipment and connectivity • Make the system easier to navigate by standardising referral pathways, using shared care plans and My Health Record • Improve collaboration between community, primary, and hospital services • Record consistently, and strengthening handovers between hospitals, primary care, community services and aged care • Consider the role of service directories and navigation roadmaps for local support

“I am not advised when my patient has been admitted to hospital or has in fact died in hospital.” - GP

Key area for action	Alignment to documented need	Opportunities for consideration
2. Workforce capacity	a. Workforce shortages in rural NSW including specialist palliative care physicians b. Variable skills and confidence in palliative and end-of-life care delivery c. Lack of regional workforce capacity and skills mapping d. Limited remuneration and sustainability of home-based care	• Accurate workforce capacity and skill mapping for region • Workforce and community care capacity building for consistency in advance care planning • Clinical skills training and mentoring opportunities for health professionals and RAC staff • Acknowledge the role of volunteers in community support and service integration • Community care capacity building in health and death literacy

"We often don't use telehealth because of connectivity issues, equipment shortages patient reluctance." - RN

Key area for action	Alignment to documented need	Opportunities for consideration
3. Consumer awareness and advanced care planning	a. Health and death literacy gaps among consumers and carers b. Low uptake of advance care directives and planning tools c. Limited guidance for consumers and families d. Missed opportunities for early and proactive conversations e. Low community grief and bereavement literacy	• Build community death literacy through local, place-based education and conversations • Promote advance care planning earlier and make it routine, not crisis driven • Provide clear, practical guidance for consumers and families about what to expect and where to get help • Normalise early end-of-life conversations in community and primary care settings • Use place-based community development approaches tailored to local needs and culture • Expand community awareness actions to include grief and bereavement support

"Knowing what to expect early with mums' deterioration would have made a big difference with the whole palliative care experience." - Carer

Key area for action	Alignment to documented need	Opportunities for consideration
4. Cultural safety	a. Aboriginal and Torres Strait Islander peoples and CALD communities face cultural, language and trust barriers b. Cultural safety gaps for Aboriginal patients; lack of liaison staff, limited culturally safe spaces and late engagement c. Insufficient Aboriginal and multicultural workforce representation d. Need for co-design and locally led solutions	• Engage Aboriginal and Torres Strait Island people and people from CALD and LGBTIQA+ communities in co-design • Redesigning service delivery through regional working groups that explore solutions that will increase access • Contribute to building cultural responsiveness • Increase Aboriginal liaison roles and cultural competency training

"For some people cultural and spiritual needs may be more important than meeting physical needs." - Aboriginal Health Worker

"Within some CALD communities, there is a hesitancy to visit a GP to discuss advance care planning due to the taboo nature of discussing death and dying." - Service provider

Key area for action	Alignment to documented need	Opportunities for consideration
5. Carer support	a. Home-based care preferred but creates significant stress for carers b. Insufficient carer recognition and structured support: practical, emotional, and medication guidance lacking, increasing risk of burnout c. Gaps in education, navigation support, respite and bereavement care	• Recognise carers as essential partners • Partnerships with Carer Gateway and Carers NSW to raise the profile of carers to primary health • Embed holistic in-home assessments and leverage volunteer networks

"The opportunity never presented to me; mum was in an RACF and my role as carer was never mentioned/acknowledged." - Family member

Key area for action	Alignment to documented need	Opportunities for consideration
6. System and service integration	a. Poor system integration across sectors b. Limited uptake of telehealth models for care c. Limited use of enabling mechanisms such as MBS items	• Strengthen links and shared processes across hospitals, primary care, community services and aged care • Make better use of enabling funding mechanisms (including relevant MBS items) to support coordination, case conferencing and home-based care • Advocate for specific MBS items for general practice Consider what MBS items can be utilised to positive effect • Strengthen the system and service integration section to include aged care funding pathways
7. Data and quality improvement	a. Limited access to timely, consistent and relevant local data b. Poor understanding of the workforce across the region c. Lack of shared understanding, service availability and outcomes d. Limited use of enabling mechanisms such as MBS items and telehealth	• Strengthen regional joint planning and enhance data-sharing capabilities across partners • Consider development of a shared regional map of the workforce and services to clearly show capacity, gaps and priorities • Use provider mapping to identify where needs are greatest across the region • Partner to improve shared data and reporting so service availability, activity and outcomes are visible across sectors

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Appendix 1: Key definitions

Palliative Care	Palliative care is a treatment approach which aims to prevent and relieve suffering and improve quality of life of those with life-limiting illness (AIHW, 2022)[14]. Palliative care can be delivered by a wide range of health and community providers, is not limited to any specific condition, can be delivered at any stage of illness, and can accompany curative treatments. It is holistic considering the person's physical, emotional and spiritual needs and aspires to be delivered in the setting of the person's choice - at home, in hospital, in a specialist palliative care inpatient unit, or in a residential aged care home.
Paediatric Palliative Care	Paediatric palliative care is a specialised area of palliative care that provides active, holistic care for a child's body, mind, and spirit, while also supporting their family. Care begins at diagnosis and continues regardless of whether disease-directed treatment is provided.
Specialist Palliative Care	Services are provided by clinicians who have advanced training in palliative care. The role of specialist palliative care services includes providing direct care to people with complex palliative care needs, and providing consultation services to support, advise and educate non-specialist clinicians who are providing palliative care.
End-of-life	This includes physical, spiritual, and psychosocial assessment, and the care and treatment delivered by health professionals and ancillary staff/services. It includes support for families and carers, and care of the person's body after their death. People are approaching the end-of-life when they are likely to die within the next 12 months and up to where death is imminent (within hours or days) and those with: • advanced, progressive, incurable conditions • general frailty and co-existing conditions • conditions with risk of sudden acute deterioration. Life-threatening acute conditions caused by catastrophic events.
Terminal	The Australian Commission on Safety and Quality in Health Care[15] defines dying as "the terminal phase of life, where death is imminent and likely to occur within hours or days, or occasionally weeks."

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