

Needs Assessment

# Palliative Care

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## Disclaimer

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## 1 Introduction

### Purpose

The purpose of this needs assessment is to gain a comprehensive insight into the main health and service needs for palliative care in South Western Sydney (SWS).

The project seeks to understand the knowledge, attitudes and practices of primary care clinicians and consumers of primary care to better understand barriers, enablers and priority areas to improve palliative care and the uptake of advance care planning in SWS.

This project will guide future service commissioning of palliative care and inform local needs assessment works.

### Objectives

1. Identify the barriers and gaps in accessing palliative care and advance care planning in SWS
2. Identify the enablers to enhance utilisation of advance care planning in SWS
3. Develop a series of recommendations to improve palliative care service provision in SWS

### Background

SWS facilitated a palliative care needs assessment in the pilot phase of the Peace of Mind project. Its findings were reported in the [Peace of Mind Project Report \(2021\)](#) reported on an implementation plan with four key components:

- Health Pathway and accessible resources
- Education
- Palliative care quality improvement
- Informal support networks

SWSPHN has extended on these components throughout the Greater Choice for at Home Palliative Care Measure timeline. Table 1 outlines key projects and initiatives implemented across SWSPHN since the publication of the Peace of Mind project report.

**Table 1. Palliative care projects and initiatives delivered by SWSPHN between 2022-2025**

Project/Initiatives	Key Activities	Progress
<b>Community Awareness</b>		
<b>ACP Education</b>	<ul style="list-style-type: none"> <li>Deliver key information on Advance Care Planning (ACP)</li> </ul>	<ul style="list-style-type: none"> <li>3 education sessions delivered in 6 different languages:                             <ul style="list-style-type: none"> <li><b>September 2023- 348 total</b> (English 57, Vietnamese 104, Mandarin 22, Cantonese 39, Arabic 76, Greek 50)</li> <li><b>October 2023- 220 total</b> (English 41, Vietnamese 46, Mandarin 21, Cantonese 36, Arabic 41, Greek 35)</li> <li><b>November 2023- 220 total</b> (English 36, Vietnamese 56, Mandarin 11, Cantonese 33, Arabic 50, Greek 34)</li> </ul> </li> </ul>
<b>Dying to Know Day</b>	<ul style="list-style-type: none"> <li>SWSPHN is a key stakeholder in the Dying to Know Day Expo</li> </ul>	<ul style="list-style-type: none"> <li><b>2025 Expo:</b> <ul style="list-style-type: none"> <li>Approximately 280 attendees:                                     <ul style="list-style-type: none"> <li>33% spoke Vietnamese at home</li> <li>11% spoke Arabic at home</li> <li>29% from Fairfield LGA</li> </ul> </li> <li>Post event survey indicated that:                                     <ul style="list-style-type: none"> <li>100% of attendees confident in making end-of-life plans and having conversations around death and dying</li> </ul> </li> </ul> </li> <li>Positive impact on 98% of attendees ‘understanding of end-of-life issues’</li> </ul>
<b>Wollondilly Café Connect: You Only Die Once: end-of-life planning workshop</b>	<ul style="list-style-type: none"> <li>Workshop to discuss Advance Care Planning and End-of-Life Planning</li> </ul>	<ul style="list-style-type: none"> <li>11 community members attended the workshop</li> </ul>

**Health Resource Directory**

- Review and updates made to patient resources within HRD
- 4 fact sheets available in English, Arabic, Simplified Chinese and Vietnamese

**Workforce Capacity Building**

**Continuing Professional Development (CPD)**

- Improve knowledge and awareness for supporting palliative care patients (inclusive of those with dementia)
- **Dementia Diagnosis and the 3D's (dementia, delirium and depression):**
  - 7 GPs (Bowral)
  - 20 GPs (Camden)
- **Explore behavioural and psychological symptoms of dementia, and what it feels like to have dementia using Virtual Reality Face to Face event:**
  - 6 GPs and 5 Nurses (Bowral)
  - 15 GPs (Camden)

**Education as part of the Core Palliative Care medicines project: Webinar series**

- Education delivered in webinar format
- **The Role of Anticipatory Medicines in Care of Patients with Life-Limiting Illness:**
  - 26 GPs
- **An Interdisciplinary approach to palliative care in South Western Sydney:**
  - 24 GPs
- **An Interdisciplinary approach to palliative care in South Western Sydney:**
  - 19 nurses
- **Supporting Palliative Care in South Western Sydney:**
  - 52 pharmacists
- **An interdisciplinary approach to palliative care in South Western Sydney:**
  - 27 pharmacists

**PainCheck app**

- Provide subsidised subscriptions to the PainCheck app for small RACHs to enable them to better identify pain and palliative care needs in patients, particularly those with limited communication capacity
- 100% subsidised PainCheck app in 3 RACHs across SWS (929 beds)

**Service Access**

<b>CORE Palliative Care Program</b>	<ul style="list-style-type: none"> <li>Increase access to core palliative care medicines by developing an interactive map of community pharmacies that stock the five core palliative care medicines, and education and awareness for community pharmacies and GPs.</li> </ul>	<ul style="list-style-type: none"> <li>55 community pharmacies (28% of regional total) signed letter of intent to stock at least one full box of each medication</li> </ul>
<b>Priority Populations</b>		
<b>Sorry Business Booklet</b>	<ul style="list-style-type: none"> <li>Launched and updated 'A Journey into Sorry Business' booklet for Aboriginal and Torres Strait Islander peoples to understand preferences for death, cultural practices and protocols associated with death.</li> </ul>	<ul style="list-style-type: none"> <li>Utilised by Aboriginal Health Workers across SWS</li> <li>Positive feedback has been received</li> </ul>
<b>Easy Read Document</b>	<ul style="list-style-type: none"> <li>Designed for people who are not familiar with English or English is a second language, people with low literacy and people with a learning disability</li> </ul>	<ul style="list-style-type: none"> <li>Facts about Dementia: <ul style="list-style-type: none"> <li>Sheet launched 8 March 2024</li> <li><i>Only Dementia Easy Read Document available nationally.</i></li> </ul> </li> <li>Facts about <a href="#">Advance Care Planning</a>: <ul style="list-style-type: none"> <li>Sheet launched 1 July 2024</li> </ul> </li> <li><i>Only ACP Easy Read Factsheet available in NSW.</i></li> <li>Presentation on dementia (9 attendees)</li> <li>Presentation on end-of-life planning (10 attendees)</li> </ul>
<b>Dementia and Palliative Care Presentations</b>	<ul style="list-style-type: none"> <li>Delivered to Macarthur Vision Impaired Group</li> </ul>	
<b>Care coordination and Integration</b>		
<b>Dementia and Palliative Care Directory</b>	<ul style="list-style-type: none"> <li>Developed dementia and palliative care service directory for community members in both hard copy and online format.</li> </ul>	<ul style="list-style-type: none"> <li>1,600 directories have been printed</li> <li>Between 1 October 2024 and 24 November 2025 the directory was downloaded 43 times.</li> <li>In that same period the following related pages were viewed: <ul style="list-style-type: none"> <li>Dementia and Palliative Care Directory: 1,422</li> <li>New directory guides carers and people living with dementia through the diagnosis: 37</li> </ul> </li> </ul>
<b>HealthPathways</b>	<ul style="list-style-type: none"> <li>Update HealthPathways to include dementia (End Stage Dementia) and mild cognitive impairment.</li> <li>Review palliative care clinical pathways.</li> </ul>	<ul style="list-style-type: none"> <li>Incorporated the CORE medicines program information</li> <li>Maintained accurate clinical and referral pathways through collaboration with the South Western Sydney Local Health District (SWSLHD) and local GPs. Top utilised palliative care pathways since (2-year period): <ul style="list-style-type: none"> <li>Non-urgent Palliative Care Specialist Referral- 177 page views</li> <li>New Palliative Care Patient- 150 page views</li> <li>Palliative Care Request- 96 page viewed</li> </ul> </li> </ul>

- Palliative Care Advice- 93 page views
- Symptom Control in Palliative Care- 75 page views

## 2 Methodology

### Data Gathering Phase

The data gathering phase included a review of population health data and literature. The South Western Sydney Primary Health Network (SWSPHN) engaged in data gathering activities to better understand palliative care, end-of-life planning, and motivations to engage in advance care planning.

#### Population Health Data

Population health data held by the Australian Government Department of Health, Disability and Aged Care, and regional population health data can be accessed through SWSPHN's data libraries. This qualitative data identified population profiles, health issues and risk factors. It also informs understanding of the previous approaches taken to improve community's access to and uptake of palliative care including advance care planning activities.

#### Literature Review

A literature review was done to identify the academic evidence-base regarding advance care planning. Literature within the Australian context was prioritised. This helped to build knowledge about advance care planning and public perceptions of it.

### Data Discovery Phase

The discovery phase included the findings from various SWSPHN consultation and co-design projects.

**Table 2. SWSPHN consultation activity findings utilised for this Needs Assessment**

Project	Methods	Cohort	Description
Advance Care Planning Consultations (August-December 2024)	Survey	<ul style="list-style-type: none"><li>8 community members</li><li>4 health professionals</li></ul>	<ul style="list-style-type: none"><li>Targeted both consumers and health professionals, including allied health and pharmacists. The survey provided an opportunity to share their perspectives on the barriers, enablers, and priority areas for advance care planning. It included translated versions for community members who cannot read English.</li><li>Promoted through online and direct email methods. It was also shared widely within SWSPHN's local networks. <i>See appendix 4 for survey results.</i></li></ul>
	Focus Groups	<ul style="list-style-type: none"><li>60 community members</li><li>31 service providers</li></ul>	<ul style="list-style-type: none"><li>Were conducted with community and service providers across the region.</li><li>Groups were representative of SWSPHN's priority groups and significant cultural groups within our region.</li></ul>
	Structured Interviews	<ul style="list-style-type: none"><li>14 participants</li></ul>	<ul style="list-style-type: none"><li>Held with accredited health professionals and service providers working in SWS through face-to-face or virtual meetings</li></ul>
	Local Health Forums	<ul style="list-style-type: none"><li>67 participants</li></ul>	<ul style="list-style-type: none"><li>SWSPHN hosts Local Health Forums twice a year. These consultations bring together community members, service providers and health professionals to discuss a selected topic. The August 2024 forums focused on palliative care.</li></ul>

			<ul style="list-style-type: none"> <li>1,234 responses were received for the 6 questions</li> <li>See <i>appendix 1 for a summary of results.</i></li> </ul>
Greater Choice for At Home Palliative Care- an Australian Government Initiative Consultations (2022 & 2025)	GP Survey (2022)	<ul style="list-style-type: none"> <li>18 GPs</li> </ul>	<ul style="list-style-type: none"> <li>Completed by GPs working across 5 LGAs including Bankstown, Campbelltown, Fairfield, Liverpool and Wingecarribee.</li> </ul>
	Consultations (2025)	<ul style="list-style-type: none"> <li>5 Residential Aged Care Homes</li> <li>Palliative Care CNC</li> <li>3 GPs</li> </ul>	<ul style="list-style-type: none"> <li>Facilitated either virtually or via formal written feedback specifically for this project</li> </ul>
	Joint SWSPHN/SWSLHD Aged Care Committee Consultation (2025)	<ul style="list-style-type: none"> <li>Representation from Pharmacy, General Practice, Specialist Palliative Care Medicine and Community</li> </ul>	<ul style="list-style-type: none"> <li>Committee consulted 19<sup>th</sup> November 2025</li> </ul>
Wingecarribee Aged Care Deep Dive (Feb-Aug 2023)	GP Survey	<ul style="list-style-type: none"> <li>9 respondents</li> </ul>	<ul style="list-style-type: none"> <li>A deep dive was facilitated in response to feedback SWSPHN received from stakeholders relating to service utilisation and challenges in coordinating care for older people within Wingecarribee.</li> <li>Wingecarribee has the highest proportion of older people to total LGA population; 27.8% of residents are aged ≥ 65 years (n= 14,701)</li> </ul>
	Service Provider Survey	<ul style="list-style-type: none"> <li>17 respondents</li> </ul>	
	Structured Interviews	Provided feedback specific to palliative care: <ul style="list-style-type: none"> <li>5 GPs</li> <li>2 PNs</li> <li>2 RACHs</li> </ul>	

## 3 Data Gathering

### 3.1 Defining palliative care in Australia

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). 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.

According to findings from the AIHW Palliative Care Services in Australia 2022-23 (SWSPHN, 2024):

- 65% of patients who died as admitted patients received palliative care
- The average patient age at admission was 75 years
- 60% of palliative care-related admissions were for people aged 75 and over and 8.3% were for people aged under 55 years
- people living in areas classified as having the lowest socioeconomic status had almost twice the rate of public hospital palliative care-related hospitalisations (44 per 100,000) than those living in the areas of highest socioeconomic status (24 per 100,000)
- 2.0% of residential aged care residents were assessed as requiring palliative care
- 1 in 1,000 GP encounters were palliative care-related

### 3.2 Defining advance care planning in Australia

Advance care planning is a voluntary and beneficial process for all individuals with informed decision-making capacity. It is about ensuring people have a choice in their future treatment decisions in the event that they are unable to speak or make decisions for themselves. Planning gives individuals the opportunity to think about, discuss and record personal values, beliefs and preferences. It helps to ensure loved ones and health care providers know what matters to a person and their treatment preferences are respected during end-of-life care.

Advance care planning is a great representation of person-centred care; the process encourages patients to be active partners in their care decisions. It can take place at any life stage, however the prevalence of completed ACPs and Advance Care Directives (ACD) is higher in older people and those living in aged care facilities (Detering et al., 2019)

There are a number of Australian federal government funded or led advance care planning initiatives which have taken place in recent years, including:

- the National Framework for Advance Care Planning Documents
- the Decision Assist Programme
- the Greater Choice for At Home Palliative Care Program
- the End of Life Discussions for Aged Care (ELDAC) Project
- national palliative care programme projects:
  - Advance Care Planning Australia
  - Advance Project
  - ACP talk: religious and culturally sensitive ACP
  - 'Dying to Know' discussion starters in English and translated
- advance care planning accreditation for acute care and aged care, via national agencies
- incorporation of advance care directives into the national electronic patient record (My Health Record).

The national framework for advance care planning documents (DoH, 2021) currently informs policy, procedures and protocols, and aims to advise on a consistent approach to planning and form design. However, there is no definitive model across the nation for advance care planning. This means there are notable inconsistencies in terminology,

forms, content and formalities around creating a plan, which poses several key challenges (DoH, 2021). The uptake of advance care planning has, therefore, been neither systematic nor widespread.

Some key barriers and challenges for Australians include difficulty accessing key planning documentation at the point of care and poor document management (al., 2023). Uptake of advance care planning also relies on awareness about the importance of having a plan in place.

There is a growing amount of evidence to suggest planning for end-of-life care is suboptimal in Australia. Only 12% of patients dying in Australian hospitals have existing ACPs (Mitchell et al., 2021). Research has also found that only half of Australian's who believe they have a valid ACP or ACD actually do have one in place (Nolte, 2023).

While many Australians prefer to die at home, advance care planning is not a routine part of care for older people. Only 29% of older Australians had any type of advance care planning document, 14% with a legally-binding ACD in place (Nolte, 2023).

Low uptake of ACDs and planning for end of life is particularly prevalent within priority populations. Barriers to planning include mistrust of the healthcare system, limited health literacy, lack of ongoing relationship with one healthcare provider, social isolation and a limited understanding of the importance of having an ACD in place.

Advance care planning empowers patients to consider and communicate their goals and treatment choices in case a time comes when they can't speak for themselves. The known benefits of advance care planning include reduced stress and anxiety for patients and family members, and an increased likelihood patients will have their wishes respected at end-of-life. There is preliminary and ongoing research which suggests engaging in advance care planning may reduce costs or become cost-neutral at end of life (Nguyen et al., 2017).

### **3.3 Defining advance care planning in South Western Sydney**

One of the fastest growing regions in New South Wales (NSW), it is estimated that South Western Sydney is currently home to 1.08 million people. This number is expected to grow to 1.4 million people by 2036 (ABS, 2022).

In South Western Sydney, there are several programs, events and workshops supported by SWSLHD, local councils and SWSPHN to support people to take part in advance care planning, including:

- The 'My Wishes' program
- Dying to know day events
- Advance care planning consultations
- Dementia workshops

Currently, South Western Sydney has a relatively young population, with only 32% over the age of 50 years, which is lower than the state rate of 36%. It is expected the number of people aged 65 years or older will reach 220,620 by 2031, an increase of 74%. Moreover, the number of people aged 85 years and over will increase by 92% (SWSPHN, 2024).

A culturally and linguistically diverse (CALD) region, South Western Sydney has one of the largest populations of culturally and linguistically diverse communities within Australia. In 2021, 42.4% of residents in SWS were born overseas compared with 34.6% for NSW (SWSPHN, 2024).

**Key insight: Advance care planning uptake is significantly lower within CALD communities.**

Engaging in advance care planning is a key challenge for CALD populations. In South Western Sydney, Bankstown,

Liverpool, Fairfield and Campbelltown LGAs are home to 43.3% of residents who were born overseas, which is higher than the state average of 34.5%. This number includes 56% of NSWs intake of refugee and humanitarian entrants.

For older Australians whose region of birth is outside Australia, there is low uptake in advance care planning. Of those who have a completed ACD, the prevalence of self-completed documentation is 25.3% whereas the prevalence of documentation completed with assistance from someone else is 48.4% (Sinclair et al., 2021).

Challenges and barriers to engaging in end-of-life planning with these groups is often due to trauma, religious beliefs, stigma and the role of family or kinship (Metro South Health, 2024). Discussions about end of life are influenced by societal and cultural values, which needs to be taken into consideration in the Western context of healthcare in Australia (Soheilipour et al., 2023) .

**Key insight: People living with a chronic or complex illness are less likely to have completed an ACP or ACD.**

In South Western Sydney, it is estimated that around one in two people (49%) are living with a chronic health condition such as cancer, diabetes, asthma or cardiovascular disease (SWSPHN and SWSLHD, 2019).

A study done in a South Western Sydney hospital has concluded that patients with motor neurone disease who were born in Australia or an English-speaking country were more likely to have completed an ACD than those born in a non-English speaking country (Phua, Ng et al., 2020).

**Key insight: South Western Sydney public hospitals performed below NSW Health in the documentation of ACPs and ACDs between July and December 2023**

Between July and December 2023, SWSLHD reported only 13.8% of patients in South Western Sydney public hospitals had ACPs documented. The NSW average for all patients in public hospitals was 25.1% (Quiroz, 2024).

Patients in South Western Sydney hospitals have reported several barriers to advance care planning (Quiroz, 2024):

- Assumption it isn't important
- Reluctance to think about death
- Lack of awareness about the seriousness of their illness
- Not wanting to burden others
- Insufficient knowledge about the importance of advance care planning
- Insufficient knowledge of health care options
- Challenges when completing forms

In the same reporting period, SWSLHD reported only 3.5% of patients in South Western Sydney public hospitals had ACDs documents. The NSW average for all patients in public hospitals was 14.9%.

### **3.4 Evidence for improved advance care planning uptake**

In Australia, and around the world, there has been a considerable effort to improve uptake of advance care planning. A systematic review of 132 advance care planning interventions globally Malhorta et al. found:

- No evidence that advance care planning has a negative effect on an individual's quality of life, however, there is no evidence that overall quality of life is improved by having an ACP or ACD
- Mixed evidence regarding the effect of advance care planning interventions on mental health, place of death and healthcare use and costs
  - Most studies found advance care planning to have no detrimental effect to mental health
  - While place of death is considered a key indication of quality of end-of-life care, not all patients prefer a home death and, in many instances, it is not feasible to achieve a home death due to practical constraints, meaning there was no consistent impact of advance care planning on place of death
  - Limited evidence on the effect advance care planning has on healthcare costs
- Positive evidence of the effect of advance care planning interventions on outcomes such as patient-health professional interaction, patient-caregiver agreement in treatment preferences, and having ACP/ACD documentation
  - Strong positive evidence that advance care planning interventions improve the quality of interactions between patients, health professionals and non-health professionals addressing negative emotions, improving understanding and trust
  - No evidence to prove interventions which simply provide information for patients are likely to change treatment preferences, however more in-depth conversations and decision aids are helpful
  - Strong evidence to suggest shared decision-making matters to patients preparing to make difficult decisions such as those at end-of-life
- Often, outcomes of advance care planning are measured by the number of ACPs or ACDs documented. However, there is more to advance care planning which should be used as a measure of a successful advance care planning intervention and taken into consideration when planning an intervention

A 2017 Australian based qualitative and quantitative study reviewed barriers to uptake, GP attitudes towards advance care planning and the usefulness of advance care planning in primary care settings. There were 1,000 GPs consulted during the study. Key findings from this report include (Coulton & Boekel, 2017):

- When people plan determines what is planned
  - ACP and ACD activities undertaken at critical timepoints in a patient's health care journey, such as at onset of a chronic disease, during a 75+ health check or entry to a residential aged care home, lead to patients being more receptive to engaging in advance care planning
  - Ad hoc planning conversations are not received well by patients and families
- Lack of knowledge of legislation and onerous forms are a barrier
  - One in five GPs agreed completing an ACD was confusing for themselves and patients
  - One in four GPs agreed legislation about advance care planning was clear and actionable
- Integrated systems and processes in practices leads to better uptake of advance care planning
  - Involving practice nurses and practice managers in the storing process
  - Multiple conversations during several visits leads to better understanding for patients and family members, as well as helping to manage expectations
  - Engaging a patient at a critical timepoint leads to further successes and supports the GP to make more certain treatment decisions moving forward

## 3.5 Health needs analysis

### Mortality

In 2023, the age-standardised rate of all-cause mortality in SWSPHN was 520.8 per 100,000 persons (6,401 deaths) (AIHW, 2025a). The top 10 causes of death between 2019-2023 combined were:

**Table 3: Leading cause of death (ICD Classification) SWSPHN, 2019-2023**

Cause of death (ICD Classification)	Deaths	ASR (per 100,000)
Coronary heart disease (I20–I25)	3,055	52.1
Dementia including Alzheimer’s disease (F01, F03, G30)	2,621	43.8
Lung cancer (C33, C34)	1,683	29.0
Cerebrovascular disease (I60-169)	1,638	28.0
Diabetes (E10-E14)	1,310	22.6
Chronic obstructive pulmonary disease (COPD) (J40-J44)	1,158	20.1
Coronavirus disease 2019 (COVID-19) (U07.1, U07.2, U10.9)	1,054	18.1
Colorectal cancer (C18-C20, C26.0)	939	16.2
Heart failure and complications and ill-defined heart disease (I50–I51)	681	11.5
Pancreatic cancer (C25)	655	11.4

### Inpatient Mortality

In 2023, there were 3,415 inpatient deaths for SWSLHD. Looking at the July to December 2023 period (Quiroz, 2024):

- Liverpool Hospital had the highest number of deaths (596)
- Braeside Hospital had the longest average length of stay (14 days)
- Bowral & District Hospital had the lowest number of deaths (78) and shortest average length of stay (9 days)
- 87.1% of deaths were anticipated due to disease progression. This is higher than the NSW rate of 73.5%
- There were 393 deaths where the discharging specialty (at time of death) was palliative care (27.2% Camden Hospital; 35.9% Braeside Hospital; 36.9% Liverpool Hospital)

### Cancer Mortality

In SWS there were 8,575 cancer related deaths between 2019 and 2023 (CINSW, 2023). The proportion of mortality was highest for the following clinical cancer groups: respiratory (21%), upper gastrointestinal (20.4%), blood cancers (11%), urogenital (10.6%) and bowel (10.5%).

Between 2019-2023, upper gastrointestinal cancer caused the highest mortality amongst females (692 deaths), followed by respiratory cancer (685 deaths). During the same reporting period, respiratory cancer caused the highest mortality in males (1119 deaths), followed by upper gastrointestinal (1054 deaths).

In 2023, the mortality rate for all cancers for males was 1.5 times higher than females (168.6 and 112.2 per 100,000 population respectively).

## 3.6 Service needs analysis

### Service mapping

The level of palliative care service provision is dependent on clinical assessment and needs of a patient. In SWS, there is a three-tiered approach to palliative care as outlined in the SWSPHN Peace of Mind Report (SWSPHN, 2021). Tables 4-5 outline the different hospital and community-based SWSLHD services available across the district:

**Table 4: SWSLHD Hospital-based palliative care services, updated November 2025**

SWSLHD Hospital-based services							
Service	Bankstown-Lidcombe	Braeside	Fairfield	Liverpool	Campbelltown	Camden	Bowral
End-of-life coordinators	✓	✗	✓	✓	✓	✗	✓
Consultative Services: onsite	✓ medical, nursing	✓ medical	✓ nursing	✓ medical, nursing	✓ medical, nursing	✓ medical, nursing	✓ medical, nursing
Consultative Services: inreach	✗	✗	✓ medical	✗	✗	✗	✗
Outpatient clinics	✓	✓	✗	✓	✓	✓	✓
Day Hospital	✗	✗	✗	✗	✗	✗	✗
Palliative Care Ward	✗	✗	✗	✓ 20 beds	✗	✗	✗
Palliative Care Unit	✗	✓ 20 beds	✗	✗	✗	✓ 10 beds	✗
Specialist Allied Health	✓ SW	✓ SW, Psychology, OT, SP, Physio, DT and Dietician	✗	✓ SW, OT, Physio, Psychology, SP and DT	✓ SW	✓ SW, Physio, Psychology, DT and SP	✗
Volunteers	✓	✓	✓	✓	✓	✓	✓

**Table 5: SWSLHD community-based palliative care services, updated November 2025**

Community-based service					
Service	Bankstown LGA	Fairfield LGA	Liverpool LGA	Macarthur Region LGA	Wingecarribee LGA
Clinical Nurse Consultants	✓	✓	✓	✓	✓
Clinical Nurse Specialists/RNs	✓	✓	✓	✓	✓
Bereavement Counselling		✓ Braeside (district wide from Braeside Hospital)			
Specialist Allied Health	✓	✓	✓	✓	✓
	SW, OT, Physio and Psychology	SW, OT, Physio and Psychology	SW, OT, Physio and Psychology	SW, OT and Psychology	SW and OT
Equipment Loan Pool	✓	✓	✓	✓	✓
Volunteers	✓	✓	✓	✓ Camden	✓

### Primary care delivered palliative care

Palliative care services can be provided by General Practitioners within the community and Residential Aged Care Homes (RACHs). Ascertaining the number of palliative care services is difficult as there are no palliative-care MBS items that can be utilised by GPs or other medical specialists providing palliative care (AIHW, 2025b).

In SWS, approximately 14.2% of the GP workforce (159 GPs not including registrars) have an indicated special interest in palliative care (SWSPHN, 2025a). Furthermore, only 5.9% have reported to SWSPHN training completion or extensive experience in palliative care. The highest proportion of GPs with indicated training or extensive experience in palliative care is within Wingecarribee.

**Table 6 SWSPHN primary care palliative care interest and training, by LGA (SWSPHN, 2025a)**

LGA	% of GPs in LGA with Special Interest	% of GPs in LGA with Training or Extensive Experience
Bankstown	15.7%	6.1%
Camden	11.6%	3.2%
Campbelltown	17.5%	6.0%
Fairfield	15.2%	6.5%
Liverpool	10.3%	3.0%
Wingecarribee	18.8%	17.6%
Wollondilly	19.0%	4.8%

### Palliative Care Physicians

The Health Provider Directory (HPD) embedded within HealthPathways indicates that there are 15 palliative care physicians servicing SWS.

## Service utilisation

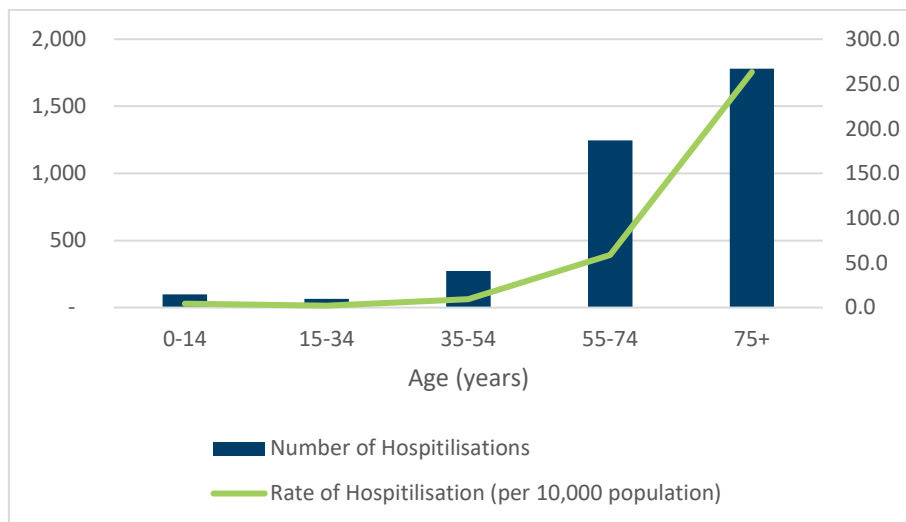
### Admitted patient palliative care hospitalisations

Admitted palliative care refers to the form of subacute care for patients with an active and advanced life-limiting illness (AIHW, 2025b). The primary purpose and treatment goal is to improve quality of life. Palliative care is managed or informed by a palliative care specialised clinician and is evidenced by a multidisciplinary assessment and management plan.

Admitted palliative care hospitalisations refer to the care provided during an episode of care in which a patient is formally admitted into hospital (public or private) to receive care and treatment.

Between 2023-2024 there were 3,461 admitted patient palliative care hospitalisations (AIHW, 2025b). The rate of admitted patient hospitalisations in SWSPHN (31.3 per 10,000 population) was lower than both NSW and national rates of service events (42.3 and 40.3 per 10,000 population respectively).

**Figure 1. Admitted patient palliative care hospitalisations 2023-2024, SWSPHN, by age group**



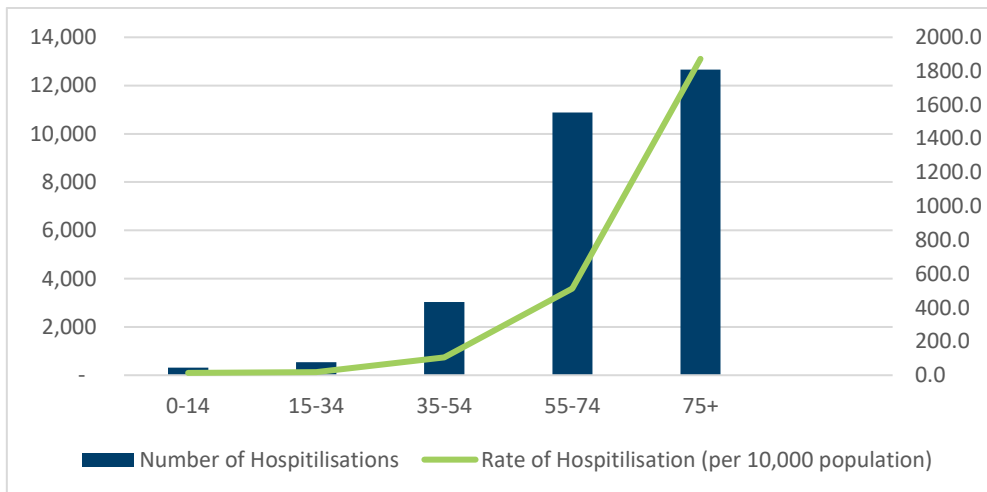
The rate of service events was higher for the most socioeconomically disadvantaged in SWSPHN 5 per 100,000 population for people living in the most socioeconomic disadvantage compared to 27.1 per 100,000 population for people living with the most socioeconomic advantage. This reflects the trend at state and national levels.

### Non-admitted patient primary palliative care hospitalisations

Non-admitted patient primary palliative care hospitalisations refers to patient treatment or consultations that are provided in an outpatient setting without formal hospital admission (AIHW, 2025b).

Between 2023-2024, SWSPHN had a lower rate of non-admitted patient primary palliative care service events (247.8 per 10,000 population) than the NSW and national rates (365.9 and 374.1 per 10,000 population respectively). This is a significant decrease compared to the SWS rates between 2022-2023 in which the rate was 403.9 per 10,000 population.

**Figure 2. Non-admitted patient palliative care hospitalisations, SWSPHN, by age group**



### Principal Diagnosis

Between 2023-2024, national data reports 60.4% of palliative care-related hospitalisations (total hospitalisations for primary palliative care and other palliative care) were non-cancer diagnoses (AIHW, 2025b). The highest recorded diagnoses were cerebrovascular disease (I60–I69) (4.3%), septicaemia (A40–A41) (4.0%) and influenza and pneumonia (J09–J18) (3.9%). All cancers (C00–C97, D45, D46, D47.1, D47.3–D47.5) represented 39.6% of palliative care-related hospitalisations. Cancer of unknown or ill-defined primary site (C26, C39, C76–C80 excl.C26.0) (9.0%) and lung cancer (C33 and C34) (5.8%) diagnoses were the highest.

### MBS

Key insights on MBS palliative care related services in SWS provided by palliative care physicians or specialists, 2023-24 (AIHW, 2025b):

- There were 1,153 palliative medicine attendances (1,085 attendances in a consulting room or hospital; 68 attendances in other settings)
- The rate of services is lower in SWS compared to the national rate (106.1 and 264 per 100,000 population respectively)
- There were only 9 palliative medicine case conferences (participation in a community case conference)
- Rates of services for all age groups '75+' and '55-74' are lower than that of NSW. However, SWS have higher rates of service for both '35-54' and '15-34' age groups than NSW ('35-54'- 59.9 and 56.7 per 100,000 population respectively; '15-34'- 13.4 and 3.1 per 100,000 population respectively)

### PBS

Key insights on PBS palliative care related medications in SWS, 2023-24 (AIHW, 2025b):

- There were 69,484 prescriptions made for palliative care-related medications from the PBSPalliative Care Schedule
- There were 22,314 people accessing palliative care-related medications
- The average number of prescriptions per person in SWS is 3.1
- Pain relief medications represented 85.1% of prescriptions (69.2%, other analgesics and antipyretics; 15.6%, anti-inflammatory and antirheumatic products, non-steroids; and 15.2%, opioids)
- The rate of prescriptions for pain relief is higher in SWS compared to that of NSW (5,338.1 and 4,436.1 per 100,000 population respectively)

- SWS has a greater rate of people prescribed pain relief medications compared to NSW (1,709.5 and 1,383.6 per 100,000 population respectively)
- The number of prescriptions per person for all medications groups are higher in SWS compared to NSW except for pain relief. The number of respiratory medications per person is considerably higher in SWS compared to NSW (8.5 and 5.7 prescriptions per person respectively)

### Pharmacy

Community pharmacies in NSW are recommended by the NSW Clinical Excellence Commission to stock the five medications on the Core Palliative Care Medicines List for NSW Community Pharmacy (SWSPHN, 2025b). The following injectable medications are available at **54** participating pharmacies across SWS:

**Table 6: Core Palliative Care Medications, NSW List**

Core Medicine	Indication/(s) for use in the last days of life
<b>Clonazepam 1 mg/mL Injection*</b>	Anxiety Terminal restlessness
<b>Haloperidol 5 mg/mL Injection</b>	Terminal restlessness Nausea
<b>Hyoscine butylbromide 20 mg/mL Injection</b>	Noisy breathing
<b>Metoclopramide 10 mg/2mL Injection **</b>	Nausea
<b>Morphine 10 mg/mL Injection</b>	Pain Dyspnoea

\* Differs to the National core palliative care medications list

\*\* Not included in the National core palliative care medications list

### Expenditure

Between 2022-2023, the expenditure on admitted patient palliative care in SWSPHN represented 4.5% (\$26,880,988) of the national expenditure. SWSPHN had the 8<sup>th</sup> highest expenditure nationally. However, the expenditure for non-admitted palliative care was \$13,421,146 which was 6.6% of national expenditure, the 3<sup>rd</sup> highest expenditure nationally.

## 4 Data Discovery

This phase involved the culmination of empirical evidence obtained by SWSPHN between 2022-2025. Consultations and surveys facilitated by the Integration and Priority Populations team were utilised to determine palliative care needs across the region.

## Identified Need: Improved care coordination and continuity of care for palliative care patients

Need	Key Consultation Outputs	Data Sources
<p><b>Reduce fragmented continuity of care</b></p>	<ul style="list-style-type: none"> <li>• The provision of palliative care is dependent on the GP. There are referrals for patient at end-of-life wanting home palliation, but bulk-billing GPs won't provide this service. This is a prominent issue within Wingecarribee in which patients with long standing GP relationships transfer into aged care facilities and may require a new GP.</li> <li>• GPs have expressed frustrations around the poor remuneration associated with palliative care service provision. The desire to provide this service in SWS is unfortunately declining.</li> </ul>	<ul style="list-style-type: none"> <li>• Wingecarribee Aged Care Deep Dive- Interviews</li> <li>• SWSLHD/SWSPHN Joint Aged Care Committee</li> </ul>
<p><b>Establish processes to better support residents receiving palliative care medication within RACH in the after-hours period</b></p>	<ul style="list-style-type: none"> <li>• The primary concerns expressed by participating RACHs were around medication charting within the after-hours period. Some key insights:               <ul style="list-style-type: none"> <li>○ Medications need to be charted by a GP or Specialist. Unfortunately, in the after-hour periods there have been instances in which residents have required palliative care medication but could not access within facility. Leading to ED transfers for medication.</li> <li>○ After-hours GPs may be reluctant to chart palliative care medications for resident's they do not know.</li> <li>○ GPs need to be involved in the pre-emptive planning before after-hours period, especially the weekend to ensure required medications have been charted.</li> <li>○ RACHs hold emergency stock, however, some medications such as morphine are not appropriate for all residents (e.g., renal impairment)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Clinician and RACH Consultations 2025</li> </ul>
<p><b>Improve communication pathways between medical and nursing staff within RACHs</b></p>	<ul style="list-style-type: none"> <li>• Effective communication between all members of a care team is critical to ensure timely and coordinated access to appropriate care and provides continuity of care and information for the resident.</li> </ul>	<ul style="list-style-type: none"> <li>• GP Survey 2022</li> </ul>

	<ul style="list-style-type: none"> <li>• Consultations have highlighted that communication, especially between GPs, Palliative Care RNs and nursing staff within facilities needs improvement:             <ul style="list-style-type: none"> <li>○ Often GPs find it difficult to locate nursing staff to communicate changes</li> <li>○ In the after-hours period, there is no palliative care support, and there is further communication delays/breakdown between GPs and nursing staff inexperienced in palliative care</li> </ul> </li> <li>• In Wingecarribee, it has been reported by GPs that there needs to be improved communication between themselves, community health and palliative care services. Especially the notification of referral acceptance.</li> </ul>	<ul style="list-style-type: none"> <li>• Wingecarribee Aged Care Deep Dive- Interviews</li> </ul>
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## Identified need: Support and build capacity within the palliative care workforce

Need	Key Consultation Outputs	Data Sources
<p><b>Continue to deliver GP targeted face-to-face and webinar CPD events</b></p>	<ul style="list-style-type: none"> <li>• CPD events facilitated by SWSPHN are valuable in building capacity of our primary care workforce.</li> <li>• Key topics of focus:             <ul style="list-style-type: none"> <li>○ End-of-life care</li> <li>○ Prescribing, titrating and educating patients/families on the importance of opioids in palliative care</li> <li>○ Palliative care in non-malignant conditions</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• GP Survey 2022</li> </ul>
<p><b>Build nursing capacity in RACHs to support outcomes for palliative residents.</b></p>	<ul style="list-style-type: none"> <li>• Aged care nurses are not mandated to perform skills that are not routinely practiced (or if they are not confident in). Identified need for aged care nurses within RACHs through consultations, specifically for Wingecarribee:             <ul style="list-style-type: none"> <li>○ Ear syringing</li> <li>○ Palliative Care</li> <li>○ Dementia</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Wingecarribee Aged Care Deep Dive- Interviews</li> </ul>

<p><b>Build clinician confidence in ongoing palliative care management</b></p>	<ul style="list-style-type: none"> <li>• Amongst, Wingecarribee GPs There is a high level of confidence in ongoing palliative care management amongst GPs providing palliative care (66.6% indicating fair to complete confidence).</li> <li>• There is need for palliative care to be considered core business within RACHs. It is essential to empower Aged Care providers to deliver on the promise of best QOL (even for end-of-life care).</li> </ul>	<ul style="list-style-type: none"> <li>• Wingecarribee Aged Care Deep Dive- Survey</li> <li>• Clinician and RACH Consultations 2025</li> </ul>
<p><b>Increase competency in recognising signs of deterioration in residents</b></p>	<ul style="list-style-type: none"> <li>• Consultations with clinicians and RACHs highlighted the imperative need for capacity building to support RNs and care staff to better recognise deterioration in residents:             <ul style="list-style-type: none"> <li>○ There are instances in which treatments have been delayed due to late detection of resident deterioration, especially for those with dementia</li> <li>○ Clear escalation pathways for deterioration should be established and reinforced, with all changes in a residents' condition being promptly reported to their GP</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Clinician and RACH Consultations 2025</li> <li>• GP Survey 2022</li> </ul>
<p><b>Better identification symptoms of palliative care within aged care to minimise unnecessary ED transfers</b></p>	<ul style="list-style-type: none"> <li>• It was emphasised throughout consultations that there are significant opportunities to better identify and manage symptoms in residents receiving palliative care, especially pain.</li> <li>• Pain is another under-recognised symptom and is not being well managed in RACHs.</li> <li>• Opioid reluctance both from families and GPs impede timely and appropriate management:             <ul style="list-style-type: none"> <li>○ GPs are heavily regulated, as are the aged care homes</li> <li>○ After-hours GPs may be reluctant if the resident is unknown to them</li> <li>○ Chemical restraint is challenging as every medicine utilised is a chemical restraint, despite resident distress and symptom levels.</li> <li>○ Recognising pain in someone with advanced dementia is also challenging</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Clinician and RACH Consultations 2025</li> </ul>

## Identified need: Improve service access by reducing barriers for community and RACH palliative care

Need	Consultation Outputs	Data Sources
<p><b>Increase accessibility of public palliative care services</b></p>	<ul style="list-style-type: none"> <li>• There is a variability in palliative care service provision across the district. The extent of this is more significant in Wingecarribee:               <ul style="list-style-type: none"> <li>○ There is need for increased community health palliative care outreach, especially in Wingecarribee.</li> <li>○ Palliative Care Clinical Nurse Consultant service not available for RACH residents within Wingecarribee. Some aged care facilities have their own palliative care nursing team, and other utilise a private provider.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Wingecarribee Aged Care Deep Dive- Interviews</li> <li>• Clinician and RACH Consultations 2025</li> </ul>
<p><b>Increase accessibility of primary care delivered palliative care</b></p>	<ul style="list-style-type: none"> <li>• GPs are pivotal in the delivery of meaningful palliative care within General Practice and community. However, there are systemic barriers that are reducing the desire for GPs to provide this service including the lack of MBS palliative care-related items, time constraints and travel for home or RACH visits.</li> <li>• Provision of palliative care is GP dependent (not provided by many bulk-billing GPs. There is an increase in palliative care referrals to GPs, especially within Wingecarribee.</li> <li>• Home visits for palliative care are expensive unless the patient has reached their safety net, there has been an indication that some GPs may feel obligated to bulk-bill in some situations which exacerbates the financial burden of providing this service.</li> </ul>	<ul style="list-style-type: none"> <li>• Wingecarribee Aged Care Deep Dive- Interviews</li> <li>• GP Survey 2022</li> </ul>
<p><b>Reduce barriers for GPs providing palliative care in RACHs</b></p>	<ul style="list-style-type: none"> <li>• Evidence demonstrates that there are barriers to the delivery of palliative care in RACHs within SWS. The top reported barriers from a GP perspective include:               <ul style="list-style-type: none"> <li>○ Difficulty locating nursing staff to effectively communicate changes</li> <li>○ Communication between Palliative Care RNs and resident's GP</li> <li>○ Lack of support and coordination between services</li> <li>○ No palliative care support in the after-hours period</li> <li>○ RN upskilling is required to support residents in the interim as it is not feasible for GPs or Specialists to attend at short notice (2-3 hours)</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• GP Survey 2022</li> </ul>

	<ul style="list-style-type: none"> <li>○ Deterioration not recognised or reporting delays - this exacerbates a resident's condition and delays appropriate treatment</li> <li>○ Difficulty prescribing breakthrough opiates</li> </ul>	
<b>Reduce barriers for GPs providing community based palliative care</b>	<ul style="list-style-type: none"> <li>● GP consultations have emphasised that time constraints and poor remuneration as the primary barriers in providing community based palliative care.</li> <li>● Unfortunately, the MBS does not reflect GP expertise for providing palliative care. This is a significant concern for those working within mainstream General Practice in which providing palliative care comes at a financial loss.</li> </ul>	<ul style="list-style-type: none"> <li>● SWSPHN/SWSLHD Joint Aged Care Committee</li> <li>● Clinician Consultations 2025</li> </ul>
<b>Increase specialist palliative care medical outreach in RACHs</b>	<ul style="list-style-type: none"> <li>● Increasing medical outreach by a specialist palliative care team would alleviate some GP pressure. Ideally, this service could provide medical support simultaneous to care provided by CNC specialist palliative care team.</li> </ul>	<ul style="list-style-type: none"> <li>● Clinician Consultations 2025</li> </ul>
<b>Increased after-hours support for RACHs</b>	<ul style="list-style-type: none"> <li>● Across multiple consultations, there were concerns about after-hours medical support for palliative care residents.</li> </ul>	<ul style="list-style-type: none"> <li>● Clinician Consultations 2025</li> </ul>

## Identified Need: Increased uptake and responsiveness to ACPs/ACDs

Need	Consultation Outputs	Data Sources
<b>Build community awareness of advance care planning including the importance of having an ACD/ACP</b>	<ul style="list-style-type: none"> <li>● The most reported barrier for advance care planning in SWS is the lack of awareness and understanding of importance and/or role in advance care planning (30% of responses for corresponding question).</li> <li>● There is a general lack of awareness of the importance of advance care planning within the community. Further to this, both consumers and health professionals lack complete understanding about their role in the advance care planning process.</li> <li>● Improving accessibility to, and awareness of ACP was widely discussed with many participants agreeing that enhancing the consumers' readiness to make a change was key to increasing uptake of advance care planning. This could be achieved through face-to-face events and opportunistic conversations with health professionals.</li> </ul>	<p>ACP Local Health Forums</p> <p>ACP- Consumer Consultations</p> <p>ACP- Service Provider Consultations</p>

	<ul style="list-style-type: none"> <li>• A vast majority of individuals that participated believe in planning for after death (writing a Will, saving money for a funeral etc.) as important, but did not associate planning for before death with their own perceived list of important things to consider.</li> <li>• Clear delineation of individual and family roles in processes were emphasised.</li> <li>• Consumers largely agree that if they had access to information through accessible channels, they would consider taking the steps to engage with advance care planning, appoint an enduring guardian or discuss implementing an ACD with a trusted supportive person.</li> <li>• Service providers are advocates for improving access to advance care planning through improved capacity building through organisations such as SWSPHN to be able to have these conversations.</li> </ul>	
<p><b>Increase support for community to better understand ACP/ACDs</b></p>	<ul style="list-style-type: none"> <li>• There is a perceived lack of information available for consumers.</li> <li>• People across the entire region noted experiencing a similar end-of-life and advance care planning journey for themselves and their loved ones. For those who had used a hospital service, needs were generally met, and they were supported when making decisions for family however, around 23% of participants noted a lack of appropriate services to support them to understand ACDs.</li> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• ACP Community Consultations</li> <li>• ACP Local Health Forums</li> </ul>
<p><b>Provide culturally appropriate education to support the diversity within the region</b></p>	<ul style="list-style-type: none"> <li>• Cultural, social and religious values and beliefs play a major role in how a person understands and plans for death. The greatest identified need for more support from within social, cultural and religious groups came from the Bankstown, Liverpool and Fairfield regions (high number of culturally and linguistically diverse population). There is also a mix of major religions, including Catholicism, Islam and Buddhism:             <ul style="list-style-type: none"> <li>○ Shame, fear or misunderstanding of what planning for end-of-life entails, including its importance, was widely discussed among participants</li> </ul> </li> <li>• Ideally, consumers would like to talk to people they trust like a GP or religious leader about their choices for end of life.</li> </ul>	<ul style="list-style-type: none"> <li>• ACP Community Consultations</li> <li>• ACP Local Health Forums</li> </ul>

<p><b>Strengthen healthcare systems to enable responsiveness to patients requiring ACP/ACDs</b></p>	<p>It is important to people living in South Western Sydney that the systems they use are equipped and able to support the individual with the advance care planning process.</p> <p><b>Support General Practice</b></p> <ul style="list-style-type: none"> <li>• It is imperative to support general practices to implement processes which identify patients in need of an ACP or ACD</li> <li>• Often there is insufficient time during a consultation to have a meaningful conversation regarding ACP</li> </ul> <p><b>Document Storage</b></p> <ul style="list-style-type: none"> <li>• There are other barriers to engaging in advance care planning conversations with patients, with many health professionals reporting a lack of clarity of how to record and store an advance care plan or directive.</li> </ul> <p><b>Transfer of ACD documentation</b></p> <ul style="list-style-type: none"> <li>• Service providers and health professionals, especially those working in hospitals and aged care facilities, advised and supported the implementation of clear policies and procedures which are in favour of improving transfer of ACD documentation when a client is admitted to hospital.</li> </ul> <p><b>Digital Infrastructure</b></p> <ul style="list-style-type: none"> <li>• Several health professionals had trouble using the online system My Health Record to store a patient’s ACP or directive. Health professionals and service providers did not feel comfortable storing a patient’s ACP, indicating a lack of clarity on their role in the end-of-life planning process.</li> </ul>	<ul style="list-style-type: none"> <li>• ACP Local Health Forums</li> <li>• ACP Health Professional and Service Provider Consultations</li> </ul>
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## 5 Determination phase

A series of recommendations were developed in response to findings collated throughout the discovery phase. Due to the immense diversity within South Western Sydney, there are several intersecting health and social concerns which could be addressed through these recommendations. There is some crossover in key priorities for health professionals, service providers and community members.

The priority rating for each action was determined using the following criteria:

- Short-term priorities are actions that SWSPHN can implement without additional resources.
- Medium-term priorities are actions that can be implemented with no to minimal additional resourcing and may require a culture shift.
- Long-term priorities are actions that would require significant addition of resources and/or partnerships.

### Recommendation 1: Improved care coordination and continuity of care for palliative care patients

Aim: Enhance patient-centred care through effective coordination of patient care between different services across the region.

Action	Outputs	Priority
1.1 Address the fragmented continuity of care for RACH residents	RACH introductions forming part of the information packs to support GP Registrar interest in providing services	Short-term
	Education delivered through SWSPHN communication channels, CPD events and GP Registrar packs on available resources that indicates MBS items that can support the provision of palliative care. <a href="#">Care Search, 2025 (MBS items support GP Palliative Care provision in primary care)</a>	Short-term
	Continue implementation of GPACI program to attract more GPs to deliver services in aged care	
1.2 Administration of palliative care medication in the after-hours period	Anticipatory prescribing by GPs	Medium-term
	Explore medication systems that enable this	Short-term
1.3 Support GPs to fully implement telehealth	Provide video telehealth consultations to residents in RACH in situations where the GP is not available for urgent face-to-face	Medium-term
1.4 Consider adoption of an existing Palliative Care Navigator service model to support people who want to die at home	Coordination of services including GP appointments, Specialist Palliative Care appointments, medication and medical equipment	Long-term
	Understand the health system and navigate information to support families	

## Recommendation 2: Support and build capacity within the palliative care workforce

Aim: Develop a competent workforce in which clinical staff are working top of scope, thus improving palliative and end-of-life care outcomes for patients within SWS.

Action	Outputs	Outcome	
2.1	Increase GP education and training to support palliative patients within community and RACHs	Develop and facilitate CPD events at SWSPHN for GPs aiming to improve earlier recognition of deterioration, timely management of palliative symptoms and advance care planning uptake. Key topics could include: <ul style="list-style-type: none"> <li>- Advance care directives</li> <li>- Diagnosing dementia and cognitive issues</li> <li>- De-prescribing</li> <li>- Patient emotional wellbeing</li> <li>- End-of-life care</li> <li>- Prescribing, titrating and educating patients/families on the importance of opioids in palliative care</li> <li>- Palliative care in non-malignant conditions</li> </ul>	Short-term
2.3	Maintain clinical referral pathways within HealthPathways to support GPs	Review clinical and request pathways in collaboration with SWSLHD Palliative Care team within recommended review period.	Short-term
2.2	Build nursing capacity in RACHs to support improved patient outcomes.	Raise awareness through SWSPHN Aged Care Newsletter of available online learning modules and training opportunities	Short-term
		Continue the implementation of education delivered by Specialist Palliative Care team at a larger scale and covering more regions of SWS	Medium/long- term
		Recognise Champions within each facility to drive palliative care (developing and implementing escalation pathways, scoping training opportunities etc.)	Medium-term

## Recommendation 3: Improve service accessibility for community and RACH palliative care

Aim: Address the palliative care service accessibility issues across the region

Action	Outputs	Outcome	
3.1	Improve access to palliative care medications	Updating and promoting the NSW Core Medicines Map on SWSPHN website	Short-term
		Imprest Medication Systems	Short-term
3.2	Effectively plan for resident's care in the after-hours period to reduce unnecessary hospital presentations	Disseminate and promote the RACH Toolkit	Short-term
		Imprest Medication Systems	Short-term
		Encouraging health professionals to complete/review Advance Care Planning appropriately following changes in the resident	Medium/Long-term
3.3	Increase access to primary delivered palliative care	Education delivered through SWSPHN communication channels, CPD events and GP Registrar packs on available resources that indicates MBS items that can	Short-term

		support the provision of palliative care. <a href="#">Care Search (2025)</a>	
3.4	Improve access to palliative care information	Continue to deliver Dying to Know Day Expos at different SWS locations	Short-term
		Dissemination and promotion of Dementia & Palliative Care Booklet	Short-term
		SWSPHN representation at relevant council events and promote existing resources	Short-term
		Continue to deliver community and provider-based education around advance care planning and palliative care	Short-term

## Recommendation 4: Increased uptake and responsiveness to ACPs/ACDs

**Aim 1:** Improved community understanding of the importance of advance care planning and key information to consider engaging in advance care planning

**Aim 2:** Improved service provider and healthcare professional capacity and responsiveness to advance care planning

**Aim 3:** Improved policies and processes for health professionals and service providers to ensure individuals engage in advance care planning.

Action	Outputs	Outcome	
<b>Build community capacity to engage in advance care planning</b>			
4.1	Develop decision aids which highlight the importance of advance care planning in accessible formats	Develop decision aids in the following formats to fill gaps in current offerings online: <ul style="list-style-type: none"> <li>- Audio</li> <li>- Translated</li> <li>- Video</li> <li>- Print</li> <li>- Web copy</li> <li>- Easy read</li> </ul>	Short-term
4.2	Develop targeted campaign to promote importance of advance care planning	Use digital and traditional media to raise awareness about importance of advance care planning, shared via: <ul style="list-style-type: none"> <li>- SWSPHN newsletters</li> <li>- Service provider newsletters</li> <li>- SWSPHN social media</li> </ul> Direct mail out to service providers	Short-term
4.3	Deliver tailored education for people with chronic or life-limiting illness living in an aged care home	Develop education package for patients with chronic diseases	Medium-term
		Develop education package for patients with a life-limiting illness	
		Engage service provider to deliver monthly education sessions at aged care homes within SWS	
4.4	Deliver tailored education for CALD populations	Engage bilingual community educators (BCEs) to deliver education in language at identified community organisations	Medium/long-term

4.5	Develop targeted campaign to promote importance of advance care planning	Use digital and traditional media to raise awareness about importance of advance care planning, shared via: <ul style="list-style-type: none"> <li>- SWSPHN newsletters</li> <li>- Service provider newsletters</li> <li>- SWSPHN social media</li> <li>- Direct mail out to service providers</li> </ul>	Short-term
4.6	Support pharmacists to engage in advance care planning conversations	Enhance pharmacists understanding of advance care planning and their role in engaging consumers	Medium-term
		Engage pharmacists to act as a key point of access for initiating advance care planning conversations and giving advice to patients regarding: <ul style="list-style-type: none"> <li>- Responsible use of medicines</li> <li>- Advice on managing adverse effects of medicines at end of life</li> <li>- Medication review</li> </ul>	Medium-term
4.7	Deliver face to face psychosocial support for identified community groups	Contract a provider to deliver psychosocial supports to already existing community groups, with emphasis on: <ul style="list-style-type: none"> <li>- Storytelling about end-of-life planning</li> <li>- Goal setting</li> <li>- Stress relief</li> </ul>	Long-term
		Engage with councils to provide space for activities	
4.8	Deliver face to face education sessions	Engage a service provider or specialist to deliver pilot program akin to the successful 'My Care My Choice' program delivered by Metro South Health in Queensland: <ul style="list-style-type: none"> <li>- Monthly, 1 hour long, free education sessions at community health centres</li> <li>- Topics include: <ul style="list-style-type: none"> <li>o When you might need an ACD</li> <li>o Why it's important to plan</li> <li>o Why it's important for friends and family to understand</li> <li>o What's the difference between an ACP, an ACD, a Will, power of attorney and an enduring guardian?</li> </ul> </li> </ul>	Long-term
4.9	Support religious and community leaders to engage in conversations about importance of advance care planning with community	Enhance religious and community leaders understanding of advance care planning and their role in engaging consumers	Long-term
		Engage religious and community leaders to act as a key point of access for initiating advance care planning conversations and giving advice to individuals including: <ul style="list-style-type: none"> <li>- How to incorporate advance care planning awareness into sermons, community events and small group discussions</li> <li>- The importance of planning for death</li> <li>- The role of faith/cultural values</li> </ul>	
<b>Build workforce capacity and responsiveness to support advance care planning</b>			
4.10	Organise CPD event to engage GPs and inform about advance care planning processes	Deliver CPD event to GPs and practice nurses, focusing on: <ul style="list-style-type: none"> <li>- Providing clarity on who is responsible for each role in the process</li> <li>- Education on where and how to store documents</li> </ul>	Short-term

		<ul style="list-style-type: none"> <li>- Support on how to talk to patients with cultural humility</li> </ul> Support on how to start and continue conversations	
4.11	Equip health professionals with resources to enhance community access to advance care planning	Develop a webpage on SWSPHN website, including: <ul style="list-style-type: none"> <li>- Information for health professionals</li> <li>- Tools</li> <li>- Resources</li> </ul> Webinars	Short-term
		Improve GP, practice nurse and practice manager awareness of The Advance Project and encourage them to undertake the free, online course	
4.12	Equip service providers with resources to enhance community access to advance care planning	Develop a webpage on SWSPHN website, including: <ul style="list-style-type: none"> <li>- Information for service providers</li> <li>- Tools</li> <li>- Resources</li> </ul> Webinars	Short-term
4.13	Deliver cultural responsiveness training To service providers engaging with First Nations community members	Improve workforce understanding of and responsiveness to cultural beliefs and understandings of health and wellbeing for First Nations individuals	Short-term
4.14	Engage residential aged care service providers to discuss current practices, needs and support them to engage in end-of-life planning	Improve residential aged care service provider awareness of and utilisation of government funded, online courses and toolkits: <ul style="list-style-type: none"> <li>- The Advance Project</li> <li>- End of Life Directions for Aged Care (ELDAC) toolkits</li> <li>- palliAGED – palliative care evidence for aged care</li> </ul>	Medium-term
<b>Strengthen systems to ensure quality of access</b>			
4.15	Support general practices to implement processes which identify patients in need of an ACP or ACD and a palliative care approach	Practice managers engaged to facilitate new/improved processes within the clinic	Medium-term
		GPs encouraged to open discussion or review plans at certain times, including: <ul style="list-style-type: none"> <li>- A diagnosis of a life-limiting illness</li> <li>- A change in a patients place of residence to an aged care facility</li> <li>- A negative change in the patient’s perception of their quality of life</li> <li>- A negative change in the patient’s condition</li> <li>- During a 75+ health check (or 55+ for Aboriginal and Torres Strait Islander people)</li> </ul>	Medium/long-term
4.16	Support residential aged care service providers to implement processes to ensure residents have a completed ACD	Encourage residential aged care service managers to implement processes and policies that ensure residents have a valid and completed ACD before being transferred to a hospital	Medium-term
		Provide helpful tools and resources to managers of residential aged care services to support valid completion of an ACD	Medium-term

	prior to being admitted to hospital		
<b>4.17</b>	Support community aged care providers to implement processes which ensure clients have commenced their advance care planning process	Support community nurses to implement procedures during home care visits aimed at engaging participation in advance care planning	Medium/long-term

## 6 References

ABS (2022). Census Data 2021, Australian Bureau of Statistics.

Australian Institute of Health and Welfare. (2022). *The last year of life: patterns in health service use and expenditure*. Retrieved from <https://www.aihw.gov.au/reports/life-expectancy-deaths/the-last-year-of-life-health-service-use-patterns>

AIHWa (2025). *Mortality Over Regions and Time (MORT) books*. Retrieved from <https://www.aihw.gov.au/reports/life-expectancy-deaths/mort-books>

AIHWb (2025). *Palliative care services in Australia*. Retrieved from <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia> Cancer Institute NSW. Cancer Statistics NSW. [www.cancer.nsw.gov.au/detailed-cancer-incidence-mortality-nsw](http://www.cancer.nsw.gov.au/detailed-cancer-incidence-mortality-nsw) [cited: 26/11/2025]

CARESEARCH (2025). Health Professionals, Palliative Care Knowledge Network.

Coulton, C., & Boekel, C. (2019). *Research into awareness, attitudes and provision of best practice advance care planning, palliative care and end of life care within general practice. 2017*.

Detering, K. M., Buck, K., Ruseckaite, R., Kelly, H., Sellars, M., Sinclair, C., Clayton, J. M., & Nolte, L. (2019). Prevalence and correlates of advance care directives among older Australians accessing health and residential aged care services: multicentre audit study. *BMJ open*, *9*(1), e025255. <https://doi.org/10.1136/bmjopen-2018-025255>

DoH (2021). National framework for advance care planning documents. Canberra, Australian Government Department of Health.

Hemsley, B., Meredith, J., Bryant, L., Wilson, N. J., Higgins, I., Georgiou, A., ... & McCarthy, S. (2019). An integrative review of stakeholder views on Advance Care Directives (ACD): Barriers and facilitators to initiation, documentation, storage, and implementation. *Patient education and counseling*, *102*(6), 1067-1079.

Klingler, C., in der Schmitt, J., & Marckmann, G. (2016). Does facilitated Advance Care Planning reduce the costs of care near the end of life? Systematic review and ethical considerations. *Palliative Medicine*, *30*(5), 423-433.

Malhotra, C., Shafiq, M., & Batcagan-Abueg, A. P. M. (2022). What is the evidence for efficacy of advance care planning in improving patient outcomes? A systematic review of randomised controlled trials. *BMJ open*, *12*(7), e060201.xw

Metro South Health. (2024, March 19). *Advance Care Planning (ACP) from a multicultural perspective, Health Equity and Access Team, Strategic Partnerships. Queensland Government*. [https://www.health.qld.gov.au/\\_\\_data/assets/pdf\\_file/0022/1353154/acp\\_from\\_a\\_multicultural\\_perspective\\_-\\_lorella\\_piazzetta\\_-\\_acp\\_week\\_24.pdf](https://www.health.qld.gov.au/__data/assets/pdf_file/0022/1353154/acp_from_a_multicultural_perspective_-_lorella_piazzetta_-_acp_week_24.pdf)

Mitchell, I., Lacey, J., Anstey, M., Corbett, C., Douglas, C., Drummond, C., Hemsley, M., Mills, A., Scott, C., Slee, J. A., Weil, J., Scholz, B., Burke, B., & D'Este, C. (2021). Understanding end-of-life care in Australian hospitals. *Australian health review : a publication of the Australian Hospital Association*, *45*, 540–547. <https://doi.org/10.1071/AH20223>

Nguyen, K. H., Sellars, M., Agar, M., Kurrle, S., Kelly, A., & Comans, T. (2017). An economic model of advance care planning in Australia: a cost-effective way to respect patient choice. *BMC health services research*, *17*(1), 797. <https://doi.org/10.1186/s12913-017-2748-4>

Nolte, L. (2023). "Landmark ACP Prevalence Research Project wraps up." Retrieved 13 December, 2024, from [https://www.advancecareplanning.org.au/about-us/news/landmark-acp-prevalence-research-project-wraps-up#:~:text=Overall%20we%20found%20that%20binding%20advance%20care%20directive%20\(ACD\)](https://www.advancecareplanning.org.au/about-us/news/landmark-acp-prevalence-research-project-wraps-up#:~:text=Overall%20we%20found%20that%20binding%20advance%20care%20directive%20(ACD))

Phua, C. S., Ng, A., Brooks, C., Harrington, Z., Vedam, H., Huynh, T., Seccombe, D., Aouad, P., & Cordato, D. (2021). Prevalence and factors associated with advanced care directives in a motor neuron disease multidisciplinary clinic in Australia. *Postgraduate medical journal*, 97(1151), 566–570. <https://doi.org/10.1136/postgradmedj-2020-138184>

Quiroz, D. (2024). *End of Life (EOL) Report July - December 2023*. SWSLHD.

Sinclair, C., Mann, J., Reymond, L., & Sansome, X. (2023). Advance Care Planning in Australia: Progress in research and implementation. *Zeitschrift fur Evidenz, Fortbildung und Qualitat im Gesundheitswesen*, 180, 111–114. <https://doi.org/10.1016/j.zefq.2023.05.012>

Sinclair, C., Sellars, M., Buck, K., Detering, K. M., White, B. P., & Nolte, L. (2021). Association Between Region of Birth and Advance Care Planning Documentation Among Older Australian Migrant Communities: A Multicenter Audit Study. *The journals of gerontology. Series B, Psychological sciences and social sciences*, 76(1), 109–120. <https://doi.org/10.1093/geronb/gbaa127>

Soheilipour, S., Jang, K., de Vries, B., Kwan, H., & Gutman, G. (2023). A Confluence of Cultures: Advance Care Planning in Long-Term Care Settings. *Journal of Long-term Care*, 0(), 120–134.

SWSPHN. (2021). *Peace of Mind Project report*. Peace of Mind Project report 2021

SWSPHN. (2024). *SWSPHN 2022-2025 Needs Assessment 2024 Update*.

SWSPHN. (2025a). *Qlik Dashboard- SWS GP Workforce*.

SWSPHN. (2025b). *Palliative care core medicines for home use*. <https://swsphn.com.au/primary-care-resources/palliative-care-resources-for-gps/palliative-care-core-medicines/>

SWSPHN and SWSLHD. (2019). *South West Sydney: Our Health - An in-depth study of the health of the population now and into the future*, SWSPHN. SWSLHD. [SWS Our Health in depth.pdf](#)

## 7 Appendix

### Appendix 1- Advance Care Planning Local Health Forums

**Table 1: Barriers, enablers and opportunities for enabling advance care planning (Local Health Forums)**

Priority	Barriers	Enablers	Opportunities
1	Lack of awareness and understanding of importance and/or role in advance care planning (30%)	Improved health systems, policies and procedures at GP and other aged care specialists (26%)	Opportunistic education for consumers e.g., conversations with GP, religious leader or community service provider (40%)
2	Social, cultural or religious beliefs and values determining the way people talk about and plan for death (24%)	In person events e.g., workshops, guest speakers, community stalls (22%)	Systematic changes to enable and encourage healthcare providers to engage in advance care planning with consumers (22%)
3	Shame, fear or misunderstanding about planning for death (11%)	Accessible resources to assist in writing an ACD (12%)	Newly commissioned service to undertake advance care planning discussions and assist with completing and storing documents (20%)

Note: Each percentage represents the proportion of all answers

### Appendix 2- Advance Care Planning Consumer Consultations

**Table 2: Barriers, enablers and opportunities for enabling advance care planning (Consumer consultations)**

Priority	Barriers	Enablers	Opportunities
1	Lack of understanding of importance and/or role in advance care planning (93%)	Cultural, social and religious beliefs considered when having conversations about planning for end of life (71%)	GP and service provider training and support to integrate planning into routine visits (100%)
2	Lack of accessible information and planning tools for consumers and family members (86%)	Opportunistic conversations between patients, families and GPs/service providers (43%)	Provide culturally appropriate and accessible education for community members (86%)
3	Lack of clarity about how to record, store or transfer an ACD for consumers and support people (50%)	Improved health systems, policies and procedures at GP and other aged care specialists (57%)	Collaboration with community organisations and public figures to raise awareness of importance (71%)

Note: Each percentage represents the proportion of all answers

## Appendix 3- Advance Care Planning Health professional and service provider consultations

Priority	Barriers	Enablers	Opportunities
1	Conversation is uncomfortable for clients/patients (86%)	Greater public awareness and access to information about advance care planning (71%)	GP and service provider training and support to integrate planning into routine visits (85%)
2	Social, cultural or religious beliefs and values determining the way people talk about and plan for death (71%)	Greater support for students who are studying to work in health care or provide a service (63%)	Improve capacity of service providers to support advance care planning, including in language support and tools (75%)
3	Lack of clarity about advance care planning, how to record and store ACPs and ACDs and who should be making decisions (63%)	Access to interpreters, translations or a support person in healthcare settings (54%)	Improve policies and procedures for transfer of information into hospitals from other health professionals and service providers (70%)

Note: Each percentage represents the proportion of all answers