

Report

# Local Health Forum

Understanding end-of-life in South Western Sydney

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# INTRODUCTION

South Western Sydney Primary Health Network (SWSPHN) facilitates two rounds of Local Health Forums a year. Each round of forums has a different area of focus. Community members, service providers and local health professionals are invited to come together to discuss priorities, service needs and gaps within our region. Forums are held at locations across the region to better understand the unique health needs of our diverse community. Insights from the forums inform the SWSPHN needs assessment and future planning for enhanced primary care.

The goal of local health forums is to:

1. Broaden grassroots consultation in our region
2. Showcase SWSPHN programs and initiatives
3. Collect strong qualitative data to inform planning and needs assessment
4. Support other co-design projects
5. Gain a better understanding of where to invest funding

The focus of this round of forums was [understanding end-of-life care in South Western Sydney](#), with a core focus on improving health outcomes for underserved and vulnerable groups in our region. SWSPHN understands the population of the entire region is growing and with an ageing population, demand for end-of-life services is rising. The purpose of this round of consultations was to better understand the enablers and barriers which impact end-of-life care in South Western Sydney and to find key priorities for our region.

Objectives of this consultation include:

1. To identify the barriers and gaps to accessing end-of-life care planning
2. To identify the enablers to enhance the quality and utilisation of end-of-life care planning
3. To develop a series of recommendations to support delivery and uptake of end-of-life care planning

Insight from this round of consultations will assist with SWSPHN's ongoing needs assessment, future strategic planning, and support a deep dive into advance care planning.

# CO-DESIGN METHODOLOGY

## COMMUNITY CONSULTATION

The face-to-face consultations were held at three locations between August and September in 2024:

- Peppers, Bowral: 20 August
- Rydges, Campbelltown: 5 September
- Rydges, Bankstown: 10 September

These were held in the evening to opportunistically capture a wider range of community members, service providers and health professionals who could attend. Each consultation was a two-hour session (2x 15 minute presentations, 1x 90 minute consultation) with dinner included.

Please note: Upon review of the first forum, the questions were changed slightly to get a better understanding of end-of-life care in South Western Sydney.

### Focus areas and consultation questions

There were four main areas of focus, incorporated into six questions asked at the forums.

#### Focus areas:

- Personal experiences
- Facilitators and enablers
- Barriers and challenges
- Opportunities for improvement

#### Questions at Bowral forum:

1. What may stop people from accessing palliative care services?
2. What could make it easier to access palliative care?
3. Why do you think people living in South Western Sydney find it hard to do advance care planning?
4. What could make it easier to do advance care planning?
5. What is important to you when thinking about end-of-life?
6. How can end-of-life care be improved in South Western Sydney?

#### Questions at Campbelltown and Bankstown forums:

1. What is your experience of palliative care in South Western Sydney?
2. How can we improve access to palliative care services?
3. Why do you think South Western Sydney has lower rates of people completing advance care planning?
4. How can we make it easier to do advance care planning?
5. What is important to you when thinking about end-of-life care?
6. How can end-of-life care be improved in South Western Sydney?

#### Forum structure

**Presentation phase:** A member from the Executive team provided an overview of SWSPHNs strategic goals, showcasing programs and initiatives aligned with delivering better access to primary health care in our region. A member from the Integrated and Priority Populations team provided a brief deep dive into the state of end-of-life planning in our region.

**Consultation phase:** Forum participants were asked a series of six questions and given time to discuss each as part of small groups facilitated by a member of the SWSPHN team.

# FINDINGS

## COMMUNITY CONSULTATION

Thematic analysis was used to quantify the data gathered from community consultations. Common themes raised for each focus area were noted and key priorities were established.

There were **67 attendees** and **1, 234 responses** to the questions asked.

**Please note:** A question about the patient experience was not asked at the Bowral local health forum so we cannot make a comment on how people living in Bowral and surrounding areas experience palliative care services.

**Table 1: Top responses to each focus area, represented by region**

Focus areas	Experience	Barriers and challenges	Enablers and facilitators	Key priorities
All local health forums	Lack of appropriate services or supports	Lack of community awareness	Improved systems, consumer education	Education for consumers
Bankstown	Lack of appropriate services or supports	Social, cultural and religious beliefs	Consumer awareness and attitude, support from service providers	New or improved services
Campbelltown	Lack of appropriate services or supports	Lack of community awareness	Consumer education and awareness	Education for consumers
Bowral		Lack of community awareness	Consumer education and improved systems	Education for consumers

### Experience of end-of-life planning and palliative care in our region

The end-of life planning and palliative care experience for people living in South Western Sydney is similar across all regions who were asked about this. Around a quarter (23%) of participants noted there is a lack of appropriate services or support to meet their individual needs. After-hours' care and the number of beds allocated to palliative care patients in our regions' hospitals was a key concern.

However, for those who have used a palliative care service in a hospital, the overall experience of the patient is generally good, and needs were met. Those who have a knowledge of the appropriate supports for their loved ones also noted a positive experience overall.

### Barriers and challenges to advance care planning

The main barrier to advance care planning, as experienced by people living in South Western Sydney, is a lack of awareness about the importance of planning for end of life. Close to one third of participants (30%) agree, many highlighting misunderstanding the processes involved with, and the importance of planning for end of life.

Social, cultural and religious beliefs are a main barrier to engaging in advance care planning with support from health professionals. This barrier was primarily raised in the Bankstown (32% of participants) and Campbelltown (28% of participants) forums. Importantly, it should also be considered that people who have different beliefs around death and dying often take part in planning but do not label it as such. A challenge for engaging individuals with strong cultural, religious or social beliefs is often mistrust of the health system or faith in someone/something else making decisions for end of life.

Other barriers mentioned include the process being too complicated or time consuming, terminology and medical information being confusing, and a shame or fear of death.

## Enablers and facilitators to advance care planning

Enablers and facilitators for advance care planning can be mapped by four levels of influence; individual, interpersonal, provider and systems. Each of the responses to questions relating to this key theme can be mapped to one of these influences.

At an **individual level**, 24% of participants agree that education and public awareness is key to enabling people to engage in advance care planning. Readiness to make a change was highlighted as a determinant of whether an individual would or would not engage in advance care planning. Through greater education, including multiple channels to engage individuals e.g. through workshops, social media advertisements and opportunistically by leveraging existing programs.

At the **interpersonal level**, 22% of respondents indicate that people would engage in advance care planning for themselves if they were invited to participate in public events, group discussions or by having more conversations with their healthcare providers.

At the **provider level**, participants indicate they would engage in advance care planning if more GPs and nurses were more educated around advance care planning and how they can support the individual to engage in planning. This sentiment is also applied to faith and community leaders. Close to a quarter (24%) of Participants indicated that the systems in which end of life planning takes place need improvement to engage more people in planning. Some examples of this include having compulsory conversations with primary care providers as part of routine health checks and updating policies.

## Key priorities for improving end-of-life care in our region

The top priority for all three regions is **education for consumers**. Other key priorities include improving the systems and services which health professionals and community members currently use and either establishing new services to support advance care planning and end of life care or improving existing services to better meet the needs of individuals.

This sentiment was reflected across all regions with 40% of all participants agreeing that education is a key priority. Some ideas to improve consumer knowledge included normalising terminology about end of life through online and in-person campaigns, hosting more community events, and engaging appropriate community leaders to have more conversations with their community groups.

The need for new or improved services was highlighted as a key priority, especially for those who live in Bankstown (33%). In Campbelltown, there were more mixed results with participants noting they would like to see more helpful resources being created for consumers to use to plan for end of life (10%), and more support from health professionals to have appropriate conversations is important (8%). Having health professionals be supported to have conversations with patients was also identified as a priority in the Bowral region (11%).

From our conversations we can see there is an understanding and agreement that people want to know how important end of life planning is and how they can plan for end of life. In general, people want to have their choices understood and supported (21%) and to have the appropriate support around them to make those decisions (20%). In Bowral, the most important thing for participants is having appropriate, supportive resources available (27%), for example online tools and decision aids to help guide the decision-making process.

Some key comments from the forums included:

- “We need to see more people talking about end of life, it shouldn’t be scary” – Campbelltown forum
- “It’s important to ask people why they don’t want to discuss it if we want to talk to them about death and dying” – Bankstown forum
- “There should be more services or specialised teams of people available to help people” – Bowral forum

## EVALUATION

The consultation provided an excellent opportunity to network, engage, and discuss the key priorities for our region in a welcoming and safe environment. There are several distinct priorities for improving the state of end-of-life services and supports in our region, as determined by the people who engaged with SWSPHN during this consultation period.

Overall, key priorities for further consideration include:

- Increasing the amount of consumer facing information, promotion and supports available in South Western Sydney to facilitate engaging in end-of-life care planning activities
- Advocating for and improving the systems and services in which our primary care workforce deliver care to our community
- Supporting the primary care workforce to engage in end-of-life planning conversations