



# Palliative Care

## Needs Analysis



Prepared by Synergia for Wentworth Healthcare, provider of the Nepean Blue Mountains Primary Health Network (NBMPHN).

Thanks to Deborah Anselm, Sanjana Vyavaharkar, Dr David Rees (Synergia)

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While the Australian Government contributed funding for this material, it has not reviewed the content and is not responsible for any injury, loss or damage however arising from the use of or reliance on the information provided herein.

We acknowledge the traditional custodians of the lands on which we work and pay our respect to Aboriginal Elders, past, present and emerging. The Darug, Gundungurra and Wiradjuri people are acknowledged as the traditional owners of the land in our region.



Cranes are a sacred bird in Japan that are a symbol of living a long life (a 'thousand years'). Legend says that in making a thousand origami cranes your wish will be granted. Sadako Sasaki, a young Japanese girl who contracted leukaemia from the atomic bomb dropped on Hiroshima in 1945, made over a thousand paper cranes in her journey with the illness. Through Sadako's story, the paper crane has become a symbol of hope, determination, and peace.

Read more about Sadako's story and the paper cranes here:

<https://theelders.org/news/story-sadako-sasaki-and-hiroshima-peace-cranes>

<https://sadakosasaki.com/>

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STAKEHOLDER	ROLE	ORGANISATION
<b>Deborah Beirne</b>	Clinical Nurse Specialist	Hawkesbury District Health Service
<b>Avril Bowd</b>	Director of Nursing	Kurrajong and District Nursing Home
<b>Julianne Brisbane</b>	Nurse Practitioner – Supportive and Palliative Care	NBMLHD
<b>Dr Hilton Brown</b>	General Practitioner	Bowenfels Medical Practice
<b>Melissa Drury</b>	Nurse Unit Manager	Hawkesbury District Health Service
<b>Kirsten Gower</b>	Clinical Manager	Hawkesbury Living
<b>Kate Hurrell</b>	CEO	Three Tree Lodge Aged Care Service
<b>Kim Jeffers</b>	Clinical Nurse Specialist	Hawkesbury District Health Service
<b>Dr Jeyanthi Kathiresan</b>	Staff Specialist – Supportive and Palliative Care	NBMLHD (Hawkesbury Hospital)
<b>Belinda Leonard</b>	Chair of the NBMPHN Consumer and Advisory Committee	N/A
<b>Caroline Marasovic</b>	Director Clinical Operations NSW	Silverchain
<b>Dr Louise McDonnell</b>	General Practitioner / GP Clinical Lead for NBM HealthPathways	Hazelbrook General Practice / NBMPHN
<b>Kirsty Norris</b>	Registered Nurse Clinical Nurse Consultant – End-of-Life Coordinator	NMBLHD
<b>Dr Alan Oloffs</b>	Senior Staff Specialist & Head of Department – Supportive and Palliative Care	NBMLHD
<b>Linda Ora</b>	Clinical Nurse Consultant – Supportive and Palliative Care	NBMLHD
<b>Dr Sue Owen</b>	General Practitioner	Lower Mountains Family Practice, Blaxland

STAKEHOLDER	ROLE	ORGANISATION
<b>Rebecca Palmer</b>	Nurse Practitioner – Supportive and Palliative Care	NBMLHD
<b>Dr Ravindra Sahasrabuddhe</b>	General Practitioner	Practices in Hawkesbury LGA
<b>Rachel Scobie</b>	Director of Aboriginal Health – Aboriginal Health Unit	NBMLHD
<b>David Sidgreaves</b>	Pharmacist	Penrith 24 Hour Pharmacy
<b>Gobika Srikanthan</b>	Consultant Pharmacist	Portland Pharmacy
<b>Tina Thew</b>	Deputy Director of Community and Allied Health	Hawkesbury District Health Service
<b>Angela Vaughan</b>	Coordinator of End-of-Life & Palliative Care	NSW Ambulance
<b>Carolyn Wilkinson</b>	Volunteer Coordinator – Supportive and Palliative Care	NBMLHD
<b>Melissa Williams</b>	Social Worker	Belong Blue Mountains
<b>Cindy Wilson</b>	Senior Social Worker – Supportive and Palliative Care	NBMLHD

NBMLHD: Nepean Blue Mountains Local Health District

NBMPHN: Nepean Blue Mountains Primary Health Network

# EXECUTIVE SUMMARY

This report describes the needs analysis undertaken for NBMPHN to explore and understand the Department of Health and Aged Care's Greater Choice for At Home Palliative Care program.

The aim of the needs analysis has been to better understand the size and nature of the palliative and supportive care service gaps within the Nepean Blue Mountains region and why they exist. Through consultation, data analysis and modelling, the key issues were explored via system maps to identify how gaps in service provision could be addressed, according to local need. This report makes a set of recommendations to guide strategies to improve the integration of and access to palliative and supportive care services in the region.



# 1. PURPOSE

Health consulting firm Synergia was commissioned in June 2022 by the PHN to assist them to increase their understanding of at home palliative care services in their region and the need for those services. An update to the previous simulation model was proposed to assess the regional need for services for people with life-limiting conditions and to use the model to project those estimates forward 10 years.

The palliative care needs analysis process was supported by data analysis, interviews, literature scans, and discussion with key stakeholders in the Nepean Blue Mountains region.

This project has three key components:

1. The update of the simulation model to estimate need,
2. The mapping of current services, and
3. Identifying the key service issues.

The simulation model focuses on providing an estimate of the current and future prevalence of palliative care. The service mapping focuses on providing a visual overview of the nature and location of current service provision across the region, as understood from the qualitative data collected from the stakeholders. The needs analysis focuses on describing the key issues that need to be addressed in future provision of palliative care services.

Synergia undertook this work in close collaboration with the staff from NBMPHN, the Local Health District (LHD), primary care, NSW Ambulance, volunteer care services, and those working in the community. We interviewed 20 people from the region and corresponded with an additional four people through online surveys, whilst analysing relevant documentation and databases.

The development and enhancement of the simulation model involved the analysis of national and regional data focusing on All-Cause Mortality, ICD10 codes to ascertain primary underlying condition, and demographic data such as age, gender, ethnicity, and place of death. This data was incorporated into the model so that estimates of need could be calculated.

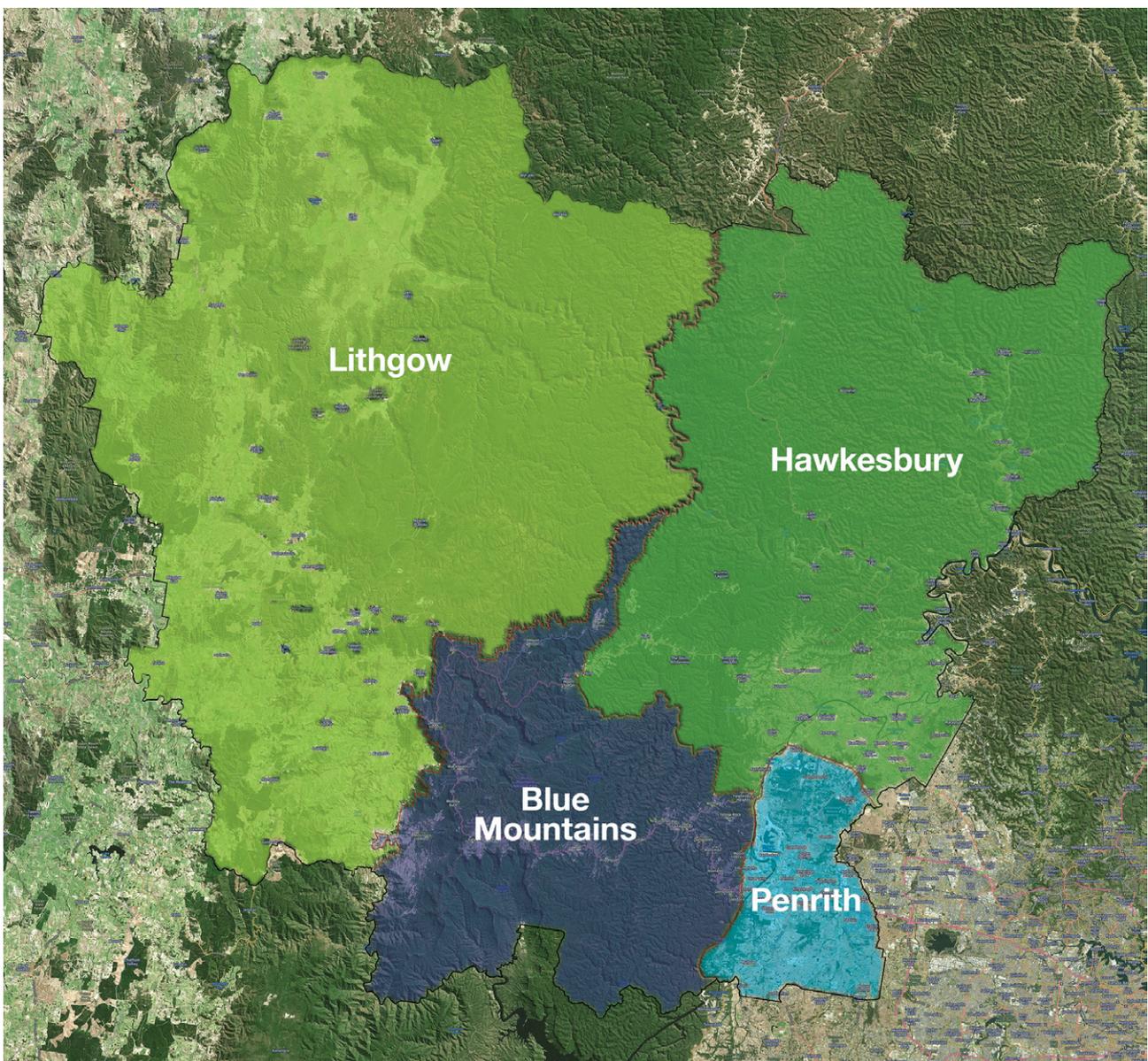
This report provides a description of the local needs and demographics within the Nepean Blue Mountains region as well as a summary of the key issues which have been identified. It highlights service provision gaps and discusses recommendations for improving palliative care services. The recommendations are intended to support the PHN with future supportive palliative care service planning and ongoing improvement of current supportive palliative care services.

## 2. BACKGROUND AND CONTEXT

The Nepean Blue Mountains region covers an area of 9,123 square kilometres, consisting of urban, rural, and regional areas. The local PHN is delivered by Wentworth Healthcare, and they are responsible for improving the health and wellbeing of people living in the Blue Mountains, Hawkesbury, Lithgow, and Penrith Local Government Areas (LGAs). Illustrated below is the layout of the Nepean Blue Mountains region that highlights the four LGAs. The estimated resident population of the Nepean Blue Mountains region as of 2021<sup>1</sup> is 385,944, of which 4.6% identify as Aboriginal and Torres Strait Islander peoples.

The traditional owners of these lands are the Wiradjuri people (Lithgow), the Darug people (Blue Mountains, Penrith, and Hawkesbury), the Gundungurra people (Blue Mountains) and the Darkinjung people (Hawkesbury).

**Figure 1: Nepean Blue Mountains region**



<sup>1</sup> Australian Bureau of Statistics, 2021 Census

The Blue Mountains LGA covers 1,431 square kilometres, with approximately 74.8% of the area designated as protected land, 99% of which is in the World Heritage-listed Blue Mountains National Park.<sup>1</sup> The LGA is bordered by Hawkesbury, Lithgow and Penrith, and is home to a community of over 78,000 people that reside across 27 towns and villages.<sup>1</sup> Almost 3% of the Blue Mountains population identify as Aboriginal and Torres Strait Islander peoples, and 17.3% were born overseas<sup>1</sup>.

The Hawkesbury LGA spans 2,775 square kilometres and is home to 67,581 residents living in urban and rural communities spread across the area.<sup>1</sup> The land is 72.5% protected, with 18.1% of the protected area being covered by one of three national parks.<sup>1</sup> The LGA shares a border with the Blue Mountains, Lithgow and Penrith. There are 65 rural and hinterland towns and villages located in the region with the main centres being Windsor, Richmond, and North Richmond. Around 4.8% of the population identify as Aboriginal and Torres Strait Islander peoples, and over 13% of the population were born overseas<sup>1</sup>.

The Lithgow LGA spans 4,512 square kilometres of which 12% is part of a national park and bordered by the Blue Mountains, Hawkesbury and Lithgow regions.<sup>1</sup> Lithgow is the largest LGA of the region, but sparsely populated by less than 21,000 people across 12 villages and hamlets (small towns)<sup>1</sup>. Lithgow has the highest percentage of people identifying as Aboriginal and Torres Strait Islander peoples in the region at 7.8%, and the lowest percentage of people born overseas at 10.1%<sup>1</sup>.

The Penrith LGA is on the western side of the Sydney metropolitan area and is the smallest LGA of the region at 404 square kilometres. It has the highest population density of the region, being home to more than 219,000 people that reside across 36 suburbs<sup>1</sup>. It is bordered by the Blue Mountains and Hawkesbury. Only 7.9% of the area is protected land with 2% of the area covered by national park.<sup>1</sup> Aboriginal and Torres Strait Islander peoples make up around 5.0% of the Penrith population, and 23.1% were born overseas.<sup>1</sup>

For people living in the Blue Mountains, Hawkesbury, and Lithgow areas there can be significant barriers to accessing healthcare services, which are centred around Penrith. This is exacerbated by the significant size of the region, limited transport options, and workforce shortages that reduce access to general practitioners (GPs) and residential aged care facilities (RACFs). The Nepean Blue Mountains LHD provides approximately 44 palliative care services across the 4 LGAs.

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<sup>1</sup> Australian Bureau of Statistics, 2021 Census

## 3. HEALTH NEEDS ANALYSIS

The Nepean Blue Mountains region aligns with four LGAs: Blue Mountains, Hawkesbury, Lithgow, and Penrith. As of 2021, the region has a population of 385,944.<sup>1</sup> The population is projected to grow by 4.9% between 2021 and 2030, taking the total number of residents living in the region to 404,672.<sup>2</sup> The projected growth in the older population for the region will increase the demand for local palliative care services.

Table 1 outlines each LGA's population size as of 2021, as well as the expected population growth.

**Table 1: Local government areas population projections<sup>1 2</sup>**

LGA	ABS CENSUS POPULATION 2021	ESTIMATED POPULATION 2030 <sup>2</sup>	ESTIMATED GROWTH
Blue Mountains	78,360	80,833	3.2%
Hawkesbury	67,581	68,827	1.8%
Lithgow	20,854	21,552	3.3%
Penrith	219,149	233,460	6.5%

### 3.1. Demography

#### 3.1.1. Age

The population of those aged 65 years and over in the Nepean Blue Mountains region is set to increase by 33% between 2021 and 2030.<sup>2</sup> The Blue Mountains region is likely to experience the highest growth in older persons by 2030.<sup>2</sup>

Table 2 and Figure 2 outline the population size based on the 2021 Census data<sup>1</sup> and expected growth<sup>2</sup> for persons aged 65 and over for each LGA, highlighting regions with an older population and regions with an expected ageing population.

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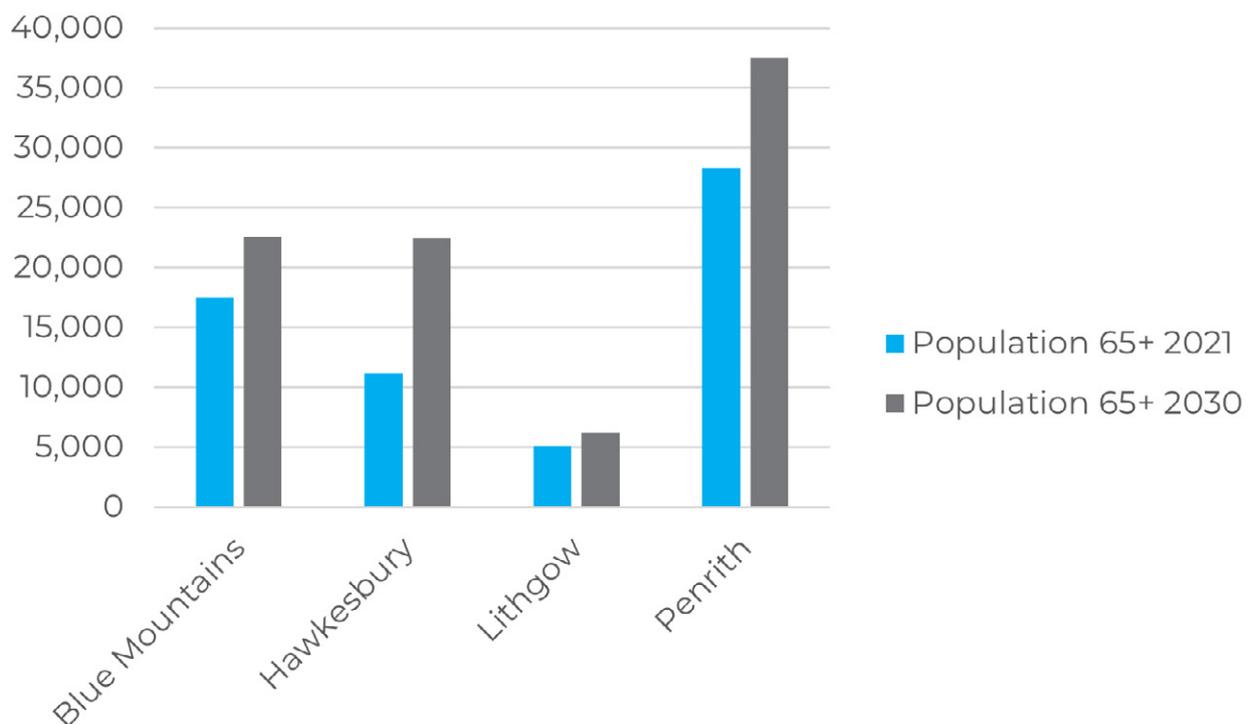
<sup>1</sup> Australian Bureau of Statistics, 2021 Census

<sup>2</sup> 2022 NSW Common Planning Assumption Projections, NSW Department of Planning and Environment

**Table 2: Population aged 65+<sup>1,2</sup>**

LGA	POPULATION 65+ IN 2021	% OF POPULATION 65+ IN 2021	POPULATION 65+ IN 2030	% OF POPULATION 65+ IN 2030
<b>Blue Mountains</b>	17,250	22.0%	22,471	27.8%
<b>Hawkesbury</b>	10,962	16.2%	14,591	21.2%
<b>Lithgow</b>	4,959	24.0%	6,214	29.4%
<b>Penrith</b>	27,743	12.7%	37,438	16.0%
<b>TOTAL:</b>	<b>60,914</b>	<b>15.8%</b>	<b>80,714</b>	<b>19.9%</b>

**Figure 2: Expected growth of population 65+<sup>1,2</sup>**



This projected growth in the older population will increase the demand for local health services and, therefore, the health workforce, particularly in the areas of aged care and at home palliative care. This is a situation the PHN and funders and providers in the region need to consider further, using the most recent data, if it is to ensure that the region's future health needs can be met.

1 Australian Bureau of Statistics, 2021 Census

2 2022 NSW Common Planning Assumption Projections, NSW Department of Planning and Environment

## 3.2. Ethnicity

Almost 18,000 people within the Nepean Blue Mountains region identify as Aboriginal and Torres Strait Islander.<sup>1</sup> This equates to 4.6% of the total population, which is higher than the NSW average of 3.4%.<sup>1</sup>

Table 3 outlines the percentage of people who identified as Aboriginal and Torres Strait Islander by LGA based on the 2021 Census data.<sup>1</sup>

**Table 3: Comparison of Aboriginal and Torres Strait Islander by LGA<sup>1</sup>**

LGA	PERCENTAGE OF POPULATION
Blue Mountains	2.7%
Hawkesbury	4.8%
Lithgow	7.8%
Penrith	5.0%

Table 4 outlines the number and percentage of people from Culturally and Linguistically Diverse (CALD) communities based on the 2021 Census data<sup>1</sup>. Around 80.5% of the Nepean Blue Mountains population were born in Australia, compared with the New South Wales average of 70.8%, with a smaller percentage of people born overseas in a predominantly non-English speaking country or with poor English skills<sup>1, 2</sup>

**Table 4: Comparison of Culturally and Linguistically Diverse Communities<sup>1, 2</sup>**

COMMUNITY TYPE	NBM POPULATION	% OF NBM POPULATION	% OF NSW POPULATION
Born in Australia	310,630	80.5%	70.8%
% Born overseas in English speaking countries	25,253	6.5%	6.3%
% Born in non-English speaking countries	50,183	13.0%	23.0%
% Born overseas poor English	4,300	1.1%	4.0%

<sup>1</sup> Australian Bureau of Statistics, 2021 Census

<sup>2</sup> Public Health Information Development Unit (PHIDU), Torrens University Australia. Social Health Atlas of Australia: 2021 Census (first release) 2022

Table 5 provides information on the number of people, by LGA, who are from CALD communities!<sup>2</sup>

**Table 5: Culturally and Linguistically Diverse Communities by LGA<sup>1,2</sup>**

<b>COMMUNITY TYPE</b>	<b>BLUE MOUNTAINS</b>	<b>HAWKESBURY</b>	<b>LITHGOW</b>	<b>PENRITH</b>
<b>Born in Australia</b>	82.7%	86.8%	90.0%	76.9%
<b>Born overseas in English speaking countries</b>	9.5%	6.0%	4.7%	5.8%
<b>Born in non-English speaking countries</b>	7.8%	7.2%	5.4%	17.4%
<b>Born overseas with poor English</b>	0.3%	0.5%	0.4%	1.6%

The LGA analysis shows a relatively higher number of Aboriginal and Torres Strait Islander peoples in Lithgow. Penrith has the highest number of people born in non-English speaking countries and correspondingly the highest number of people born overseas with poor English.

It is evident that the region has a diverse population, including Aboriginal and Torres Strait Islander peoples and people born outside of Australia. This has significant implications for the future of palliative services.

1 Australian Bureau of Statistics, 2021 Census

2 Public Health Information Development Unit (PHIDU), Torrens University Australia. Social Health Atlas of Australia: 2021 Census (first release) 2022

### 3.3. Need for Palliative Care

To provide estimates of how many people in the Nepean Blue Mountains region could benefit from palliative care, and those who are choosing to die at home, we have undertaken modelling using data from the Australian Bureau of Statistics (ABS) and applied them to the population of the Nepean Blue Mountains region.

The purpose is to provide the PHN with an estimate of the size of the need and, therefore, the potential impact of any changes they decide to make.

To calculate the numbers entering the last year of life we used all-cause mortality data from the ABS and grouped them using the ICD-10 codes to estimate both the underlying cause of death and those who could benefit from palliative care. This is a well-accepted approach to estimating need for palliative and end-of-life care.<sup>1 2</sup>

The fact that some data is only available at a national or state level, for example age-adjusted standardised death rates, means these numbers can be used as estimates only. They are not precise predictions. Despite this limitation, they do provide enough precision to support service planning.

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1 Rosenwax, L. K., Blackmore, A. M., & Holman, C. D. J. (2005). Estimating Size of Palliative Care Population\_Rosenwax. *Palliative Medicine*, 19, 556-562.

2 Morin, L., Aubry, R., Frova, L., MacLeod, R., Wilson, D. M., Loucka, M. et al. (2017). Estimating the need for palliative care at the population level: A cross-national study in 12 countries. *Palliat Med*, 31(6), 526-536.

### 3.3.1. Palliative Care Needs

In 2021, the Nepean Blue Mountains region had an estimated population of 385,944, growing to an estimated 404,672 in 2030.<sup>1,2</sup> Using the method described above, table 6 estimates the number of people in the region who could benefit from palliative care.

**Table 6: Approximate number to benefit from palliative care<sup>1,2</sup>**

LGA	2021	2026	2031
Blue Mountains	484	489	495
Hawkesbury	278	281	284
Lithgow	216	218	221
Penrith	656	664	672
<b>Total</b>	<b>1,634</b>	<b>1,653</b>	<b>1,672</b>

### 3.3.2. Dying At Home

Around 70% of Australians<sup>1</sup> would prefer to die at home, but only around 44% do, with over 50% dying in a hospital or medical service.<sup>2</sup> Using ABS data on place of death, table 7 details the deaths occurring in a person's home/residence, including RACFs, for the people of NSW in 2019.

**Table 7: NSW deaths occurring in a person's home/residence, including RACFs<sup>2</sup>**

AGE	PERCENT OF DEATHS
Under 25	22.5%
25 – 44	39.9%
45 – 64	33.1%
65 – 84	36.6%
85+	57.0%

1 Swerissen, H., & Duckett, S. (2014). Dying well. Grattan Institute.

2 Australian Bureau of Statistics, Classifying Place of Death in Australian Mortality Statistics 2019, 2021

## 4. SERVICE NEEDS ANALYSIS

### 4.1. Access to services

#### 4.1.1. Palliative care services

The NBMLHD delivers specialist palliative care services across the region, with the main hub for services operating out of Nepean Hospital in Penrith.

The LHD also provides some in-patient and outpatient palliative care services out of Blue Mountains Hospital, Hawkesbury Hospital, Lithgow Hospital and Springwood Hospital.

Community palliative care services are also funded by the LHD but are delivered via community health facilities based in Hawkesbury, Lawson, Lemongrove (Penrith), Lithgow, and Springwood.

The NBMPHN does not fund specialist palliative care services. The three main role of the PHN are:

1. Supporting general practice to provide high quality care to their patients.
2. Funding (or commissioning) local health services that meet the needs of our community.
3. Integrating the different parts of the local health system, so people don't get 'lost' when they move from one health service to another.

The PHN has a key role in identifying and addressing service gaps for their communities, to ensure care is well integrated across primary and secondary services.

The accessibility of palliative care services, particularly for people and families in rural and regional areas of the region, was a common theme across all stakeholders interviewed for this needs analysis.

The lack of accessibility of services at all levels, from specialist palliative care support through to non-clinical support, was raised as a significant barrier to enabling patients and families to stay at home through the palliative care and end-of-life process.

Whilst services are available in the main centres across the region, their ability to provide consistent and equitable services to people and families living outside of these centres is very limited.

Stakeholders report limited or no access to specialist palliative care physicians and nurses in the more regional and rural areas of the Blue Mountains, Hawkesbury, and Lithgow areas.

## 4.1.2. Out of hours support

Currently patients and families can receive nursing support at home via the community palliative care nurses, between 8:00am to 5:00pm, with telephone support available until 8pm. From 8pm to 8am, families must call the Palliative Care After Hours Helpline. Although staffed by palliative care nurses, they are not known to the patient and therefore have no prior knowledge of the patient's diagnosis, prognosis, or condition. This is not ideal as families usually call if they are in crisis, and the nurses' lack of familiarity with the patient and/or their family can lead to misinformation and significant stress.

This lack of out of hours support often leads to families calling an ambulance, which can result in the transport of their loved one to an emergency department where they may experience significant wait times.

## 4.1.3. Residential Aged Care Facilities

Palliative care is also provided in residential aged care facilities (RACFs) across the Nepean Blue Mountains region. Clinical care for palliative patients in RACFs is mostly led by the patient's GP. Patients with more complex conditions may need to be seen by the specialist palliative care team.

Many GPs currently provide significant geriatric care and palliative care support to their patients in RACFs. This will be an expanding area of need for more GPs to be available to provide this quality level of expertise in care.

Nurse practitioners from the specialist palliative care service also visit some RACFs in the region to review residents. They identify those that may be entering their end-of-life period within the next 6-12 months and support the facility to put additional care plans in place.

There is scope to improve the knowledge and expertise of RACF staff in palliative and end-of-life care, and to provide better support to the GPs leading their patient's care in these facilities.

## 4.1.4. Non-clinical services

End-of-life packages of care are available to patients entering the last few weeks of life. End-of-life packages are non-clinical packages of case management and home care services delivered through the NSW Health Out of Hospital Care (OHC) Program.

These packages provide low to medium levels of home care services for patients who are in the deteriorating or terminal phase of a life-limiting illness or condition. They include access to case management, personal care support, domestic assistance, meals, transport, social support, and in home respite for family carers.

Packages are available for up to six weeks at a time with repeat packages available to patients who require further support.

Whilst these packages provide good support for patients and families, they are limited to the last 3 months of a patient's life, which does not meet the needs of patients with conditions that lead to a slower decline in health, or where prognosis is harder to predict.

The end-of-life coordinators do have the ability to be flexible with the support provided for patients within the confines of the budget available, but some interviewees reported that there have been occasions where packages had to be withdrawn because of funding limitations.

Older patients and families may also be able to seek in home support via the 'My Aged Care' system. However, several interviewees reported that because these packages are not specific to palliative care and end-of-life needs, the staff providing them may not have the skills or knowledge to best support patients and families at this critical time. They reported that in some cases, families chose to withdraw from these services as they were unable to meet the family's and/or patient's needs.

Access to non-clinical support services at home is challenging in the more rural areas of the region with families often unable to access care or being put on waitlists for support. This is not ideal for patients requiring urgent support to enable them to die safely and comfortably at home.

#### 4.1.5. Volunteer services

There are a range of volunteer organisations that provide support to patients and families experiencing life-limiting conditions and needing palliative care in the Nepean Blue Mountains region.

A number of these organisations have their genesis within cancer care and have now widened their access to include all patients receiving palliative care.

These volunteers provide a critical service supporting people to die at home, which includes assistance with domestic work, social aspects of care, and transportation.

Due to the limited resources within the specialist palliative care services and the community services' shared care model, volunteers are often the only constant presence within the care team for patients and their families/carers.

Palliative care teams are the gatekeepers for referrals into volunteer services, meaning the need for a referral for support is determined by a medical professional who may not be fully aware of a patient's social situation and/or needs.

In the more rural and regional areas, such as Lithgow, the volunteer services are not getting many – if any – referrals for palliative care and end-of-life care support from the community teams. Our interviewees reported that due to the workload pressures in community health, the nurses are not able to take referrals for patients in early stages of palliative care and, therefore, patients and families that could benefit from volunteer support are not being identified.

Our interviewees described a desire to see staff from volunteer services as part of the wider multi-disciplinary team, working proactively with the team to identify patients who may benefit from volunteer services, including the ability to contact the team directly to discuss this.

## 4.2. Workforce

### 4.2.1. Specialist palliative care workforce

The LHD's palliative care workforce consists of staff specialists in palliative care, registered nurses (many with advanced qualifications in palliative care eg. clinical nurse consultants, clinical nurse specialists, and nurse practitioners), and allied health professionals, who work across the hospitals and community health settings in the region. At present, the community health workforce is mostly comprised of generalist nurses providing day-to-day care and case management, with the LHD's specialist palliative care workforce providing input for more complex cases.

The specialist palliative care workforce is based within the main hospital centres across the region, and whilst the community services do provide support to patients in their homes, this can be very limited for those patients and families living in more rural and regional communities.

The lack of resources was a common theme across all our interviews. Whilst there is good access to the specialist palliative care workforce within Nepean Hospital, the coverage across the regional hospitals and community teams is much more limited.

### 4.2.2. Allied health workforce

The current model of palliative care is predominately comprised of medical and nursing staff, with allied health roles making up only a small portion of the workforce. However, allied health professionals can perform many important roles within palliative care teams, including Aboriginal and Torres Strait Islander health workers and practitioners, occupational therapists, pharmacists, physiotherapists, and social workers. The inherent value for patients that would be added through an increase in the number of allied health professionals being involved in the palliative care team is well understood by those involved in the system. It is our understanding that more government funding is being made available to expand the palliative care workforce to include more allied health positions.

Currently there is only one social worker employed within the Nepean Blue Mountains palliative care service who provides support to patients and families across the region. However, they are unable to provide anything more than consultative support in most areas, rather than the wraparound psychosocial and counselling support that is needed in palliative care.

In the absence of comprehensive social work support, patients may not be aware of available services that assist them to stay safely at home. This can be an additional reason for unnecessary hospital or RACF admissions for palliative care patients.

### 4.2.3. GP workforce

Access to GP services can be limited in the Nepean Blue Mountains region, with recruitment and retention challenges creating GP shortages. It is widely understood and acknowledged that GPs are extremely busy and facing burnout challenges as a workforce. Our interviewees reported that, in some areas, GPs will travel in from Sydney and the surrounding areas to deliver services rather than being based in the local area. The shift away from a primary care model where the GP is well connected and embedded in their local communities has significant implications for people in need of palliative care.

Furthermore, the 'baby boomer' generation of Australia is undergoing a wave of retirement, so while the region continues to have GPs who live and work in their communities, managing gaps with retiring GPs is also going to be challenging.

Stakeholders, including the GPs interviewed, reported a general lack of experience in palliative care across the GP workforce, and GPs who are unaware of the current palliative care system and the services available for their patients in the region.

### 4.2.4. Residential Aged Care Facility workforce

The region is reporting RACF staff shortages, causing an unstable workforce with recruitment and retention challenges, and high turnover of staff within facilities. Challenges during COVID-19 lockdowns have also led to an increase in staff burnout, causing many to leave their employment and, at times, their healthcare career. A consequence of the staffing issues is that many nurses in the facilities are new or temporary (via agencies) and often do not know the residents well. This means that patients nearing end-of-life may not be identified early and/or there is confusion about the care plan in place for palliative care patients.

Paramedics report that they are often called to palliative care patients in RACFs in the after- hours period, when the number of staff on duty is at its lowest and it is generally hard to find someone familiar with the care plan for the patient. Without direction and guidance surrounding the patient's care plan, the paramedics often feel it is necessary to transport the patient to hospital for further care.

With workforce shortages across the region, RACFs can experience some challenges with providing geriatric and palliative care, as GP's availability to visit RACFs on an 'as needed' basis may be difficult. This means that RACF staff may have to call 'Triple Zero' if a patient is clinically deteriorating and the GP is unable to attend for urgent assessment and review. This may lead to an unnecessary hospital admission and the resident not being able to die in the RACF as per their wishes.

Representatives from RACFs also expressed the importance of GP involvement in family meetings for residents receiving palliative care. They report that whilst their staff are able to engage proactively with families about the palliative care needs of their relative, families will often express a wish to talk with the GP or a clinician overseeing care, but this is often not possible for them to arrange.

Residential Aged Care Facility staff across the Nepean Blue Mountains region are also supported clinically by two nurse practitioners. The nurse practitioners are part of the specialist palliative care service that is based at Nepean Hospital.

## 4.2.5. Volunteer and community workforce

The volunteer workforce is an essential part of the supportive and palliative care system across the region. They are often the only continuity of care for patients and families, providing social support and assistance to people choosing at home palliative care.

Volunteer services report that, post-COVID-19, their workforce has diminished and it is getting harder to find enough volunteers to adequately support palliative patients and their families in the region. Our interviewees described a highly qualified volunteer workforce with former health professionals a potentially untapped resource. They have the skill-set to undertake more advanced tasks, however volunteers are currently not allowed to provide support with personal care or medication administration.

Interviewees from the rural and regional areas also expressed the view that, with strong community engagement, the local volunteer workforce could be significantly expanded. The challenges of living rurally, coupled with recent natural disasters and the COVID-19 pandemic, have served to strengthen the goodwill and community spirit within the rural communities. Interviewees felt that this could be channelled into providing more supportive and palliative care for the area.

Across the region, but particularly in the more rural and regional areas, there is a lack of available workforce to provide support at home for personal care, domestic assistance, and meals preparation. Interviewees reported that palliative care patients and families end up on wait lists for support at home and need to rely on family and friends to provide this.

## 4.2.6. Workforce capacity building

Another theme discussed by many of our interviewees was the need for capacity building opportunities, through education and training, across the workforce involved in palliative care.

Capacity building opportunities include:

1. Understanding contemporary models of palliative care.
2. How to identify patients who may benefit from supportive and palliative care.
3. Communicating with patients and families about life-limiting conditions and end-of-life to empower decision making.
4. Pain management, including prescribing/administering medications.
5. Services available to support patients and families through the end-of-life process.
6. Supporting patients identifying as Aboriginal and Torres Strait Islander people and their families.
7. Supporting CALD patients and their families.
8. Supporting patients with disabilities and their families.

There was general agreement that improved access to palliative care-specific capacity building opportunities would be of benefit to the primary health care workforce. However, consideration of delivery mode will be important due to the competing priorities and the high demands of their roles creating challenges to attend planned education and training sessions.

## 4.3. Service mapping

A key task for the project was to map current services for palliative care in the Nepean Blue Mountains region. Two key points emerged from this work: Firstly, it was clear that the further a patient lived from Nepean Hospital, the more difficult it was for them to access services; and, secondly, providing an easily accessible list of palliative care services available in the region was seen to be an important output that this project could deliver.

The mapping data was obtained from documentary sources and interviews with health providers. The information was uploaded to a visual map that provided locality and service information for three group services:

1. Residential Aged Care Facilities (RACFs),
2. Clinicians and other health professionals providing palliative care, and
3. Community and LHD.

### 4.3.1. Service implications

Establishing access to services in the early stages of a patient's palliative care journey is crucial. However, as noted above, palliative care services are concentrated in the Penrith LGA, making access to these services for patients living outside of that area potentially challenging. Obtaining early referrals for palliative care services also appeared to be complicated by highly variable referral procedures and processes, resulting in unnecessary delays for patients.

The service mapping has highlighted the concentration of services around Nepean Hospital and the consequent difficulty many patients and their carers have in accessing services. The mapping does not comment on the quality of services, as these will be discussed in the section below.

## 4.4. Quality and effectiveness of current services

It was outside the scope of this assessment to conduct a detailed review of the quality measures and indicators for services delivering palliative care in the Nepean Blue Mountains region. However, the geography of the region and the limited resources available mean that access to at home supportive and palliative care is inequitable and out of reach for many patients and families living in rural or regional communities.

For Aboriginal and Torres Strait Islander peoples, our interviewees acknowledged large gaps in the cultural awareness and cultural competency of health services, including in palliative care. Whilst patients can access Aboriginal Liaison Officers and Aboriginal Health Workers via the LHD, these specialised staff members are limited in numbers. Therefore, patients and families engaging with services may not be offered appropriate cultural support.

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<sup>1</sup> Palliative Care Volunteering in Residential Aged Care Facilities in NSW: A sample study in Western Sydney LHD: Palliative-Care-Volunteering-in-Residential-Aged-Care-Facilities-in-NSW.pdf (volunteerhub.com.au)

Due to language and cultural barriers, patients from CALD communities were another population group identified as struggling to access palliative care services. This is despite the Penrith LGA having the highest community representation of people born overseas (in non-English speaking countries and/or with poor English) for the region, in combination with specialist palliative care services within reach of its population. The lack of confidence in accessing GP or palliative care services may lead to unnecessary hospital admissions for the management of any acute palliative care needs.

The overall assessment of the quality and effectiveness of current at home palliative care services, by the stakeholders interviewed, is that 'they do the best job they can with the resources available'.

## 4.5. Coordination and integration of services

### 4.5.1. Lack of integrated care planning

A key theme that emerged from stakeholder interviews was the difficulties faced in the absence of an integrated electronic shared care plan for palliative care patients that is accessible to everyone involved in their care. This is particularly relevant for patients wanting to stay at home for their palliative care, as they will have a range of health professionals from different parts of the health care system supporting their care at home.

Each part of the system, e.g., hospital-based services, community nursing, paramedics, GPs, pharmacists, and other primary care services, holds individual records that cannot be accessed from another part of the system. Whilst some transfer of information prevails, such as hospital discharge summaries, the lack of shared communication makes it challenging for health professionals from different parts of the system to know who is involved, who is accountable and/or coordinating care, and what the current palliative care and/or end-of-life plan is. This includes access to information regarding medication regimes and any Advance Care Directives that are in place.

The information gap creates frustrations for patients and families and can create confusion and misinformation regarding what support is being provided. In the worst-case scenarios, patients end up not receiving adequate pain relief, receiving inappropriate life preserving treatments, and/or being unnecessarily admitted to hospital when their preferred option would be to stay at home.

### 4.5.2. Interface between services

A key gap in services is the interface between specialist palliative care services and the patient's GP. Many stakeholders interviewed agreed that the GP should remain at the centre of the palliative care team providing constant support and primary care to both the patient and family throughout the palliative care process. However, GPs who are experienced in providing palliative care are well embedded in their local communities, and already have strong links with the hospital and community specialist palliative care teams.

However, as previously discussed, a recurring theme was that in parts of the region, the GP workforce is under unprecedented pressure. Many interviewees described a GP workforce that can be unstable in some areas due to recruitment and retention issues. In these areas there may be high numbers of locum GPs, or GPs that travel into the region to provide services, rather than being embedded into the local communities. Interviewees noted that the current Medicare Benefits Scheme (MBS) funding model for primary care does not support extended or after-hours consultations or home visits, making it hard for GPs to provide the type of care palliative patients need.

GPs expressed some concerns in prescribing 'drugs of addiction' to palliative patients given the high level of system scrutiny for such medications. There can be limited familiarity with the preparation and administration of some end-of-life medications which also contribute to their concern. The above issues highlight the importance of GPs being able to consistently engage with specialist palliative care teams.

Interviewees reported a disconnect between hospital-based and community-based palliative care teams due to the mixed reporting lines and silos between services. Communication from specialist services, if delayed, interferes with timely patient treatment, especially for GPs in the region.

Interviewees recounted the lack of access to both clinical and non-clinical palliative care support for patients in rural and regional communities resulting in traumatic experiences for patients, families and carers. This has resulted in GPs discouraging patients to choose at home palliative care.

It was expressed that capacity building opportunities for GPs in palliative care need to compete with education and training for myriad other health issues. The low number of palliative care patients seen each year by GPs and the presence of specialist services may make palliative care a low priority for them.

### 4.5.3. Advance care planning

A key challenge in developing an integrated care plan for at home palliative care is the inconsistency of advance care planning conversations happening across the system. This leads to Advance Care Directives not being in place and the patient's wishes regarding their end-of-life care to be undocumented or unclear.

Where Advanced Care Directives are in place, they are not always accessible to the health professionals visiting the patient at home. This is often a significant issue for paramedics who may be called by families distressed by the patient's condition and asking for life-preserving treatments that may go against the wishes of the patient.

In a general practice environment, advance care planning conversations usually occur when GPs and practice nurses consult with patients to undertake the annual 'Health Assessment for Older Persons (75+)'. However, younger patients could also benefit from these discussions and interviewees reported that limited experience and confidence across the health workforce in initiating advance care planning conversations is contributing to the low number of them taking place.

Another barrier to advance care planning conversations is the patient's or family's reluctance to accept they have a life-limiting condition. This situation can be exacerbated by health professionals remaining focused on a treatment/recovery pathway of the patient's condition until end-stage illness symptoms present. When this occurs, patients may not be referred to palliative care until the last few weeks or days of their life, significantly impacting any opportunities for advance care planning conversations.

#### 4.5.4. Coordination of palliative and end-of-life care

Another key issue raised by the stakeholders from across the system is the lack of clear case coordination for providing supportive and palliative care services to patients and families. This can lead to a perceived lack of accountability for care across the system. As previously discussed, current MBS funding, disconnects across the system, and an absence of shared care plans, prevents GPs in the region from coordinating palliative and end-of-life care for their patients, despite them being ideally placed to do so.

Due to the limited resources within the specialist palliative care services, they are unable to provide day-to-day case management or coordination for most patients. The small number of specialist palliative care nurses working within the community tend to provide care only to patients with more complex needs. This leaves most of the case management support and day-to-day at home palliative care to be provided by the generalist community nurses sitting within the community health nursing team.

The referrals for requesting community health palliative care are centrally triaged alongside all other requests for community health support. Therefore, the urgent nature of many palliative care referrals can be missed if the health professional triaging the referrals has limited or no experience in palliative care. This can then lead to a break in the continuity of care and to delays in patients receiving palliative care.

Several interviewees described the specialist palliative care services as operating under a 'shared care' model but what this means appears unclear. When a model of care is not clearly defined, it has the potential to lead to a lack of understanding as to who has ultimate accountability for the patient's care.

## 5. NEEDS ASSESSMENT

The approach to this needs assessment was built on region-wide stakeholder consultation during which we interviewed a range of people involved in palliative care. The interviews were undertaken by the project team, including people from Synergia and NBMPHN following an interview protocol designed for the specific needs of this phase of the project. The purpose of these interviews was to understand the interviewee's perspectives on:

1. What are your perceptions of the provision, across the region, of current services for at home palliative care?
2. What do you consider to be the key actions that need to be taken to achieve the overall goal of improving access to at home palliative care for those who choose that option?
3. What are the key issues that will need to be addressed for those actions to be implemented?

The issues raised in the interviews were captured and then analysed using cognitive mapping<sup>1</sup>, which is a method of exploring links between ideas. Specifically, it maps the thinking behind the three questions noted above, namely what the issues are, what is driving them and what are the consequences of them being addressed successfully or not. These maps highlight the key ideas and the lines of influence between them. An arrow from one idea to another simply indicates that one idea influences another. For example, in the cognitive map shown in the next section (figure 3) the idea 'primary care funding model makes it difficult to deliver after hours and in home care' is linked to 'home visits to patients needing palliative care support do not happen'. Simply, this is saying that because the current primary care funding model incentivises short 15-minute consultation appointments, GPs often feel unable to provide support to their patients out of hours or in their homes. This has a big impact on their ability to provide palliative care to their patients. The ideas at the bottom of the map are key drivers and indicate potential areas of interventions. Those at the top of the map are potential consequences, some desirable, some not. They provide potential goals to be strived for, and risks that need to be avoided.

The following sections outline the key themes that emerged from our interviews with stakeholders and the potential actions available to address them.

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<sup>1</sup> Eden, C., & Ackermann, F. (2004). Cognitive mapping expert views for policy analysis in the public sector. *European Journal of Operational Research*, 152(3), 615-630.

## 5.1. Key themes

### 5.1.1. Role of GPs in supporting at home palliative care

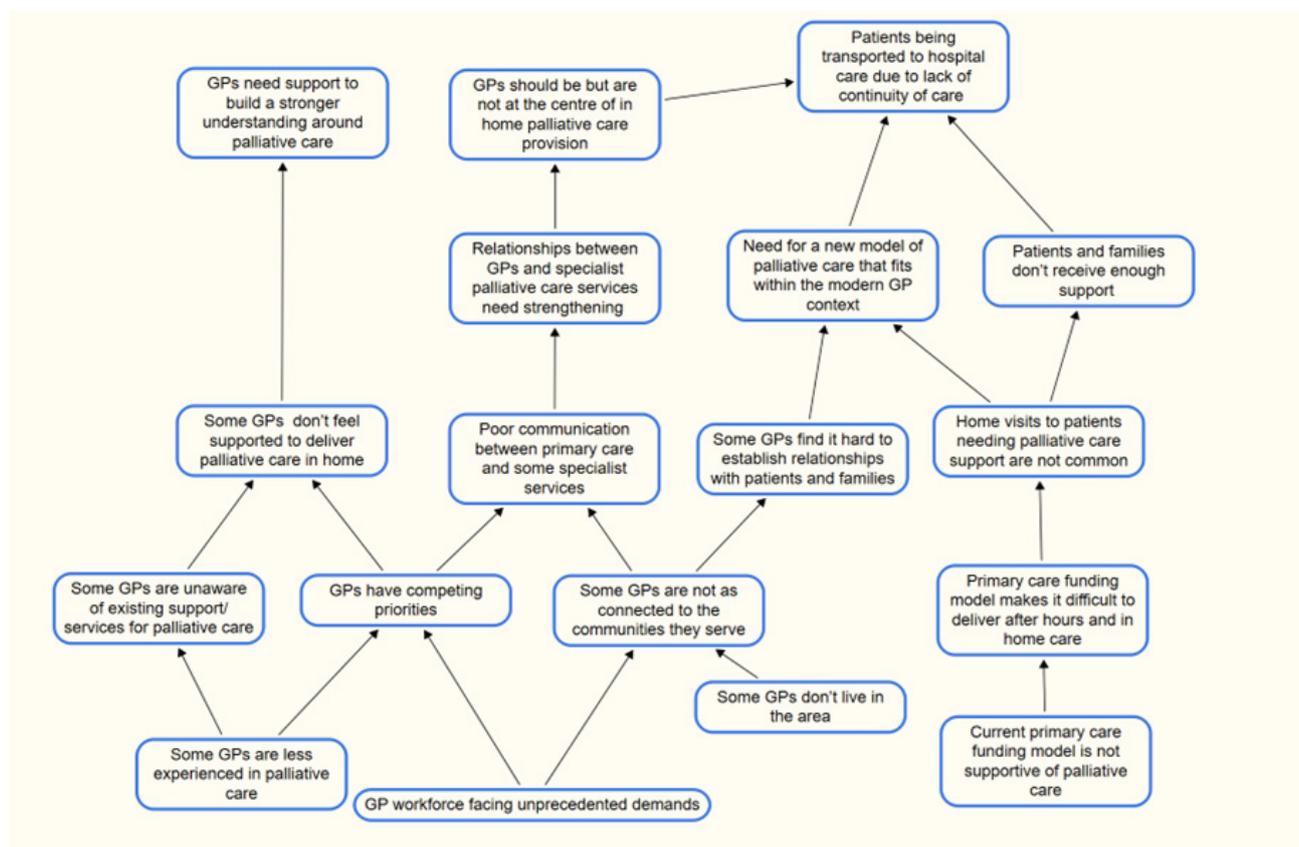
The following cognitive map describes the issues revolving around the role of GPs in supporting at home palliative care.

#### 5.1.1.1. Role of the GP: Mapping the issues

Figure 3 is a cognitive map that illustrates the connections between ideas that relate to the role of GPs in supporting at home palliative care.

At the bottom of the map are several drivers affecting GP's ability to support at home palliative care. The first relates to the relative inexperience of the GP workforce in palliative care. The next two relate to the workforce challenges that exist for primary care within the Nepean Blue Mountains region, including the unstable workforce and GPs commuting into the region to deliver services in some areas. The fourth relates to the current primary care funding model not being supportive of the needs of palliative care patients who often require access to in-person and at home support across a 24-hour period.

Figure 3: Cognitive map of the issues surrounding the role of the GP



The consequences of GPs not enabled to provide at home palliative care is that whilst GPs should be at the centre of at home palliative care for their patients and families they are often not involved.

This ultimately can lead to patients that have chosen at home palliative care not receiving enough support and being transported to hospital or other medical facilities against their wishes due to a lack of local, coordinated care. The situation is exacerbated by poor connections between GPs and specialist palliative care services, leaving GPs unclear on how best they can support their patients and/or feeling it is easier to leave palliative care to the specialist teams.

Home visits and access to palliative care out of hours are critical support services for patients wanting to stay at home. Only a small number of GPs across the region have been able to sustain home visits for some of their patients, and even these GPs need to draw the line somewhere. One GP dedicated to providing palliative care to patients conceded that those living in the most rural and regional areas are asked to meet the GP at the local hospital for treatment.

Telehealth was discussed with our interviewees and most agreed this could improve connections with patients and families living outside of the main centres. It was interesting to note that GPs have access to LGA-specific palliative care referral pathways and information via HealthPathways, however this was seldom raised by our interviewees as a commonly used source of information. The benefits of providing further capacity building activities for GPs has been previously raised in this report.

#### **5.1.1.2. Role of the GP: Potential actions**

The logic of the map highlights some potential areas suitable for PHN intervention that would build capability in palliative care within the GP community and enable GPs to maintain a central role in the delivery of services to their patients.

Potential actions to consider include:

- 1.** Review the current HealthPathways for palliative care to ensure they are providing relevant information to GPs on the region's palliative care services and referral pathways. Also ensure that they support GP decision making regarding care planning for their patients.
- 2.** Develop a communication and engagement program to ensure GPs have a good understanding of palliative care services.
- 3.** Build connections between primary and secondary care and create 'on the job' training opportunities for GPs through joint consultations, case conferencing, and the use of telehealth.
- 4.** Strengthen connections between GPs and community pharmacists to enable more education and support for GPs on palliative medications and prescribing.
- 5.** Develop GPs with a special interest in palliative care across the region to provide support to the wider GP network.
- 6.** Grow nurse practitioner outpatient clinic models to build connections with local GPs, with a focus on early referrals into palliative care services.

### 5.1.1.3. Role of the GP: Goals

The logic of the cognitive map also highlights some potential goals. These include:

1. A reduction in patients being transported or admitted to hospital where they have identified their preference is to receive at home palliative care.
2. An increase in the number of GPs engaged in palliative care.
3. An increase in the number of GPs attending capacity building events on palliative care.
4. An increase in the number of patients choosing to receive at home palliative care.

## 5.1.2. Building a more connected palliative care system

The following cognitive map describes the issues around building a more connected palliative care system.

### 5.1.2.1. Building a more connected palliative care system: Mapping

Figure 4 is a cognitive map that illustrates the associations between ideas that relate to developing a more connected palliative care system. A connected system will enable more patients to choose at home palliative care.

At the bottom of the map are several drivers affecting how connected the current palliative care system is across its different aspects. The first three drivers relate to the lack of connections and/or disconnects in the current system between hospital and community services, between secondary and primary care, and between GPs and other health providers (e.g., pharmacists). The last driver relates to the overall lack of awareness across the system of palliative care services, particularly with regards to services that can support people in choosing at home palliative care.

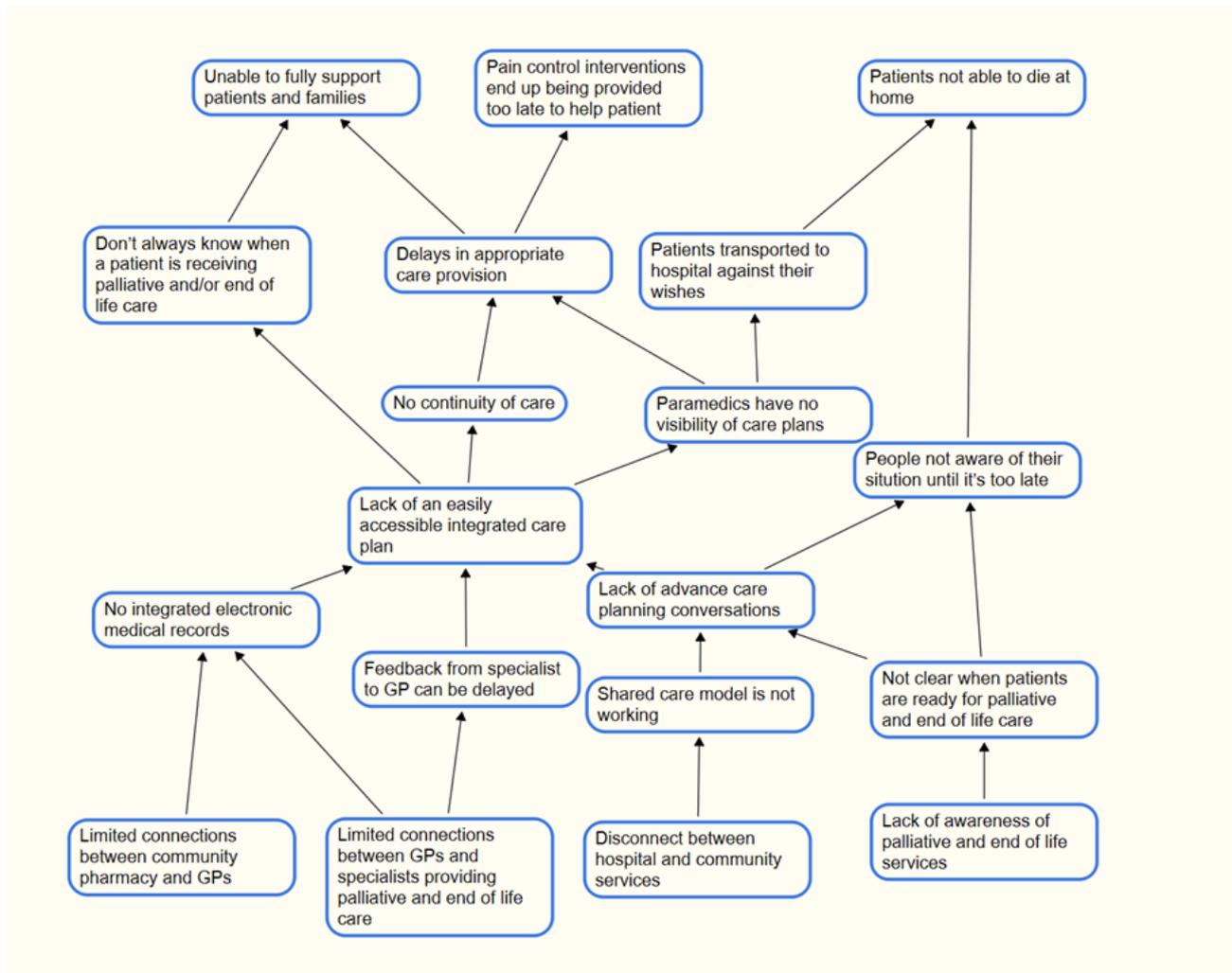
The consequences of the lack of connections across the palliative care system are that patients and families do not receive the support they need in a timely and coordinated fashion, services are reactive, and patients ultimately lose the ability to choose where they receive palliative care.

A critical component of a well-connected system is an easily accessible, integrated electronic shared care plan. This would enable everyone involved in a patient's care to access information regarding the services provided and the current care plan for the patient. A shared care plan requires an electronic platform that is accessible to all stakeholders across the system.

The lack of such a system means that information travels slowly around the care the patient receives and is not available at critical intervention points, such as when paramedics are called out to a patient's home.

Another key disconnect across the system is the lack of clear case coordination and/or case management. Our interviewees expressed frustration at the lack of accountability across the system for who is responsible for coordinating care and/or being the central point of contact for care planning. This could be the role of the GP but as discussed in the section above, GPs are currently not enabled to deliver this role.

Figure 4: Cognitive map of the connection between ideas that relate to developing a more connected palliative care system



### 5.1.2.2. A connected system: Potential actions

The logic of the map highlights some potential areas suitable for PHN intervention that would help build the overall connectiveness of the palliative care system.

Potential actions to consider include:

1. Enable a shared care plan that is accessible to everyone involved in a patient's care.
2. Develop the GP role to become the central coordinator for the care plan.
3. Build capability and capacity of GPs and nurses to develop robust Advance Care Directives with patients and their families.
4. Ensure information on the care plan is updated proactively and available to anyone visiting the home.

### 5.1.2.3. A connected system: Goals

The logic of the cognitive map also highlights some potential goals. These include:

1. Improved and more timely information available to everyone involved in palliative care.
2. A reduction in patients being transported or admitted to hospital unnecessarily where they have chosen at home palliative care.
3. Patients receive timely and appropriate access to pain relief and other interventions that support their at home palliative care plan.

## 5.1.3. Reducing inequity of access to at home palliative care

The following cognitive map describes the issues around reducing inequity of access to at home palliative care.

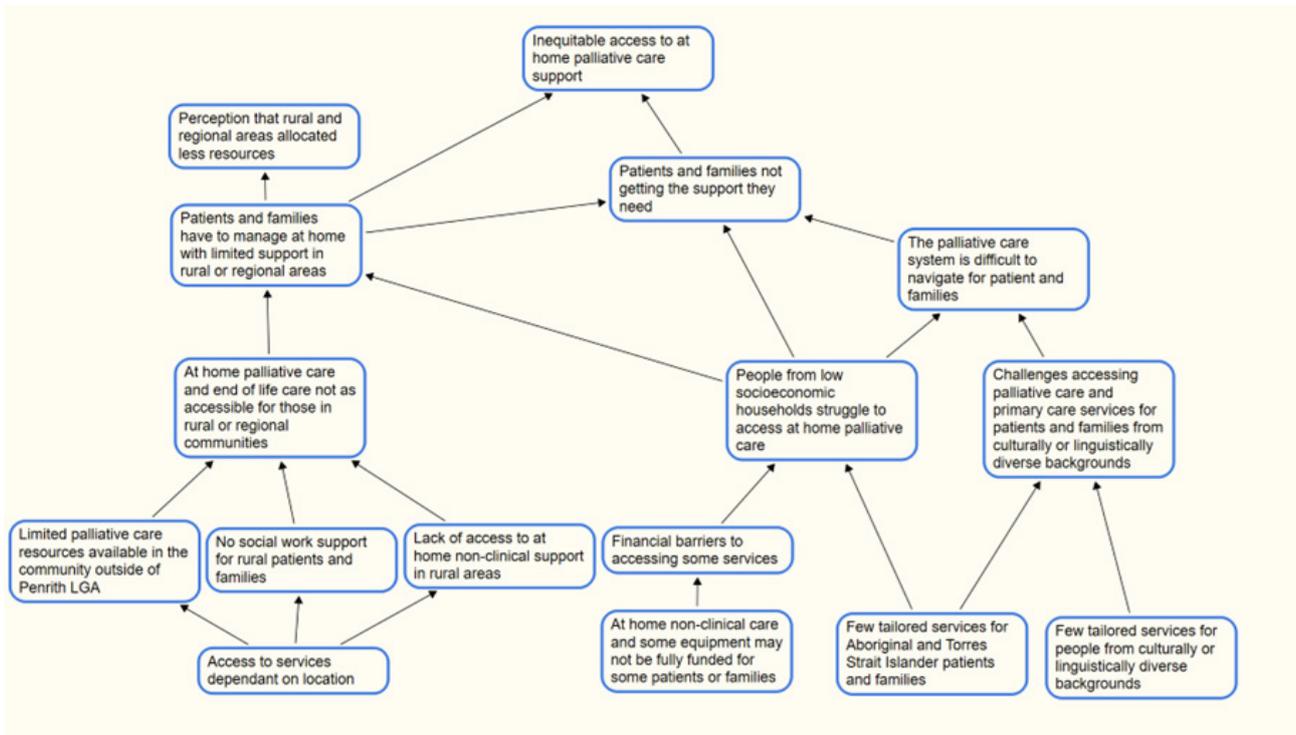
### 5.1.3.1. Reducing inequity of access: Mapping

Figure 5 is a cognitive map that illustrates the connections between ideas that relate to reducing inequity of access to at home palliative care.

At the bottom of the map are several drivers relating to the current challenges for some populations in accessing palliative care. The first barrier to access relates to the location of the patient receiving care. Those living in more rural and regional locations do not receive the same level of service as those living closer to the main palliative care services based out of Nepean Hospital in Penrith. Services (both clinical and non-clinical, including social work) are limited for patients and their families/carers outside of the main centre, leading to critical supports potentially being missed. The second driver relates to financial barriers within the system, with home-based non-clinical care, leading families from low socioeconomic households struggling to provide the wraparound care required to support their relatives to choose at home palliative care.

The final drivers in the map relate to the barriers to accessing services that exist for Aboriginal and Torres Strait Island peoples due to the limited number of Aboriginal Health Workers and/or support workers across the system and a lack of tailored services available in their communities. There is also a lack of support available for patients and families from CALD communities to access health services.

Figure 5: Cognitive map of the issues surrounding the equity of access to services



These barriers lead to significant inequities across the palliative care system. The current palliative care system is not adequately supporting people living in rural and regional locations, of low socioeconomic status, identifying as Aboriginal and Torres Strait Islander, and from CALD communities. This has led some GPs refusing to recommend the option of at home palliative care to their patients due to the traumatic experiences they have witnessed with other patients and their cares/families.

### **5.1.3.2. Reducing inequities: Potential actions**

The logic of the map highlights some potential areas suitable for PHN intervention that would help build the overall connectiveness of the palliative care system.

Potential actions to consider include:

- 1.** Build regular use of telehealth into the palliative care service delivery model to enable a more connected system and provide better support to clinicians and patients across the region.
- 2.** Build training in palliative care and use of medication pumps into RACF nurse induction training to ensure equitable access to palliative care within RACFs across the region.
- 3.** Develop accessible information on palliative care services that caters for those from CALD communities and those with disabilities.
- 4.** Implement the greater use of family meetings to discuss the palliative care and end-of-life options available, to develop a care plan, make decisions, and ensure everyone in the family group is well-informed on the services and supports available to them.
- 5.** Provide education and training to the palliative care workforce on the need for religious and cultural assessments for people entering palliative care, and how to reduce barriers to accessing services for people within their communities, including for Aboriginal and Torres Strait Island peoples, people from CALD backgrounds, and people with disabilities.

### **5.1.3.3. Reducing inequities: Goals**

The logic of the cognitive map also highlights some potential goals. These include:

- 1.** Equitable access to at home palliative care regardless of location and/or ethnicity and/or socioeconomic status.
- 2.** Patients and families are well informed on their options and the services available to them should they choose at home palliative care.

## 5.1.4. Developing a new model of palliative and end-of-life care

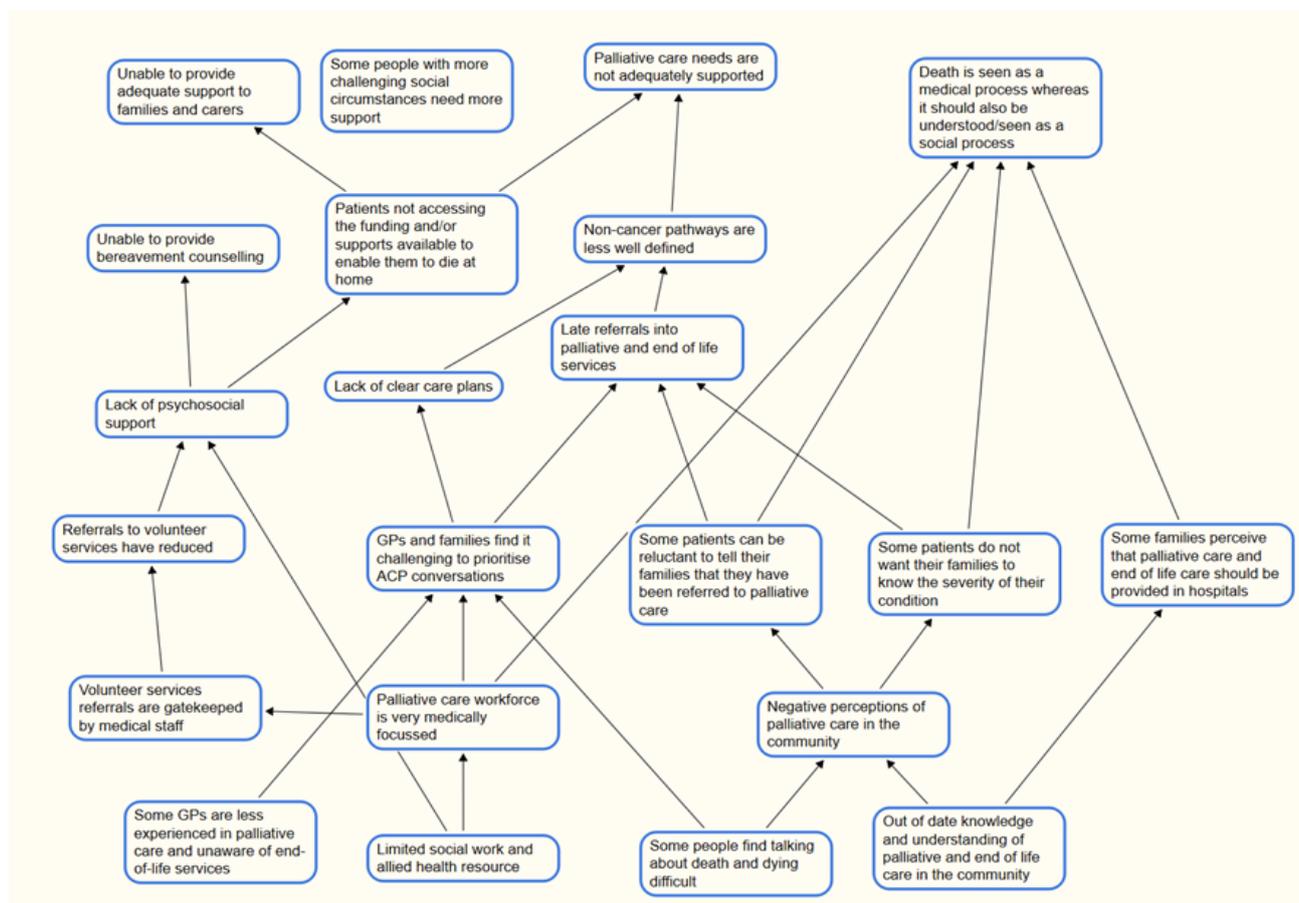
The following cognitive map describes the issues around the current model of care for palliative care.

### 5.1.4.1. Developing a new model of care: Mapping

Figure 6 is a cognitive map that illustrates the connections between ideas that relate to the current model of care for palliative care services.

At the bottom of the diagram are several drivers that have shaped the current model of care for palliative care. The first relates to the limited understanding some GPs have of the palliative care services available for their patients. The second relates to the limited social work and allied health workforce within current palliative care services. Alongside this is an underlying reluctance within the community to talk about death and dying, which is exacerbated by out-dated knowledge of palliative care services.

**Figure 6: Cognitive map of the issues surrounding the current model of care for palliative**



The palliative care system has a strong medical focus. Consequently, services are predominantly comprised of clinical health professionals, such as doctors and nurses. This means that patients and families have limited access to social work support and/or any other type of psychological or bereavement services. This is linked to volunteer services often providing the only continuity of care, and psychosocial and bereavement support to patients and their families.

The second consequence of the medical model is that it perpetuates the view of death as a medical process rather than a social process. This encourages a focus on the progression of dying instead of how services can support patients with a life-limiting illness to live well. It means that some patients are transitioned very late into palliative care, dying only hours or days later. It also makes advance care planning conversations difficult as people are less willing to speak about death and dying.

#### **5.1.4.2. Developing a new model of care: Potential actions**

The logic of the map highlights some potential areas suitable for PHN intervention that would help develop a new model of care for palliative care services.

Potential actions to consider include:

- 1.** Enable and support a more co-ordinated, community-focused model of palliative care using a broad mix of health professionals (e.g., medical, nursing, and allied health), non-clinical support, and volunteer organisations, by facilitating better connections across the system.
- 2.** Provide education into communities on death as a social process, and the role of palliative care services in supporting this.
- 3.** Ensure Advance Care Directives are completed for everyone in the community who may benefit from having one in place, through targeted training for GPs, practice nurses, and others within the system.
- 4.** Ensure all advance care planning documents are uploaded to the patient's My Health Record.
- 5.** Encourage proactive and coordinated care planning for everyone with a life limiting diagnosis, that supports the GP as the centre of the care team and early involvement of other palliative care services.

#### **5.1.4.3. Developing a new model of care: Goals**

The logic of the cognitive map also highlights some potential goals. These include:

- 1.** Communities are engaged in a broader conversation about the end-of-life and dying, and the support and choices available to them
- 2.** Increased number of advance care planning conversations and Advance Care Directives completed and stored/uploaded appropriately.
- 3.** Increased diversity of the workforce to include more allied health, non-clinical, and volunteer staff.

## 5.2. Priority actions

The key themes emerging from this needs analysis and the recommended actions were shared with NBMPHN’s Palliative Care Advisory Committee at their inaugural meeting on 17 October 2022. This group is comprised of key palliative care stakeholders from across the region.

This group endorsed the key themes and have recommended the following areas for priority action by the PHN:

KEY THEME	ACTION	RATIONALE
<b>Role of the GP in palliative care</b>	<p>Review the current HealthPathways for palliative care to ensure they are providing relevant information to GPs on the region’s palliative care services and referral pathways. Also ensure that they support GP decision making regarding care planning for their patients.</p> <p>Build connections between primary and secondary care and create ‘on the job’ training opportunities for GPs through joint consultations, case conferencing, and the use of telehealth.</p>	<p>GPs need to know what services are available to them when they need them. Creating localised service maps within HealthPathways will ensure GPs can instantly access up-to-date and accurate information on the specialist- and community-based palliative care services available to them in their region.</p> <p>There is 24/7 on-call access to a specialist palliative care consultant available to GPs and paramedics, but awareness of this was not evident in our interviews. Building awareness of this service and clear pathways for escalation that GPs, paramedics, and other community-based clinicians can follow will enable more timely access to specialist medical support for patients and families.</p> <p>There is the potential to build on the use of the ‘My Virtual Care’ app that specialist services are trialling that allows multiple participants to case conference virtually from a patient’s home or other location.</p>

KEY THEME	ACTION	RATIONALE
<p><b>Building a more connected palliative care system</b></p>	<p>Enable a shared care plan that is accessible to everyone involved in a patient's care.</p>	<p>'Care Monitor' is software that is being used in other jurisdictions to enable shared care planning across health systems. There is the opportunity to explore if this software, or similar, could be used to support shared care planning in palliative care services.</p>
<p><b>Reducing inequity of access to palliative care services</b></p>	<p>Build regular use of telehealth into the palliative care service delivery model to enable a more connected system and provide better support to clinicians and to patients across the region.</p> <p>Build training in palliative care and use of medication pumps into RACF nurse induction training to ensure equitable access to palliative care within RACFs across the region.</p>	<p>Telehealth is already being used in RACFs to enable access to specialist support for patients in rural areas. This concept could be expanded into primary care and other community locations such as the patient's home.</p> <p>High turnover of staff in RACFs across the region is leading to inequities in care delivery. Ensuring that regular training in palliative care needs and medication delivery is built into nurse induction training will reduce this.</p>
<p><b>Developing a new model of palliative care</b></p>	<p>Encourage proactive and coordinated care planning for everyone with a life limiting diagnosis, that supports the GP as the centre of the care team and early involvement of other palliative care services.</p>	<p>Pathways for patients with cancer diagnoses are much better defined. Developing clear pathways for patients with non-malignant diagnoses that support early involvement of palliative care services, and are responsive to a patient's needs rather than their diagnosis, will have a big impact on the care options available to these patients.</p>

## 6. SUMMARY

There are significant opportunities to improve access to at home palliative care across the Nepean Blue Mountains region.

The key themes highlighted by this needs assessment include:

1. Strengthening the role of the GP in the delivery of palliative care services to ensure they can guide and support their patients through their end-of-life decision making and palliative care journey.
2. Building a more connected palliative care system that is responsive and able to meet the needs of those choosing at home palliative care.
3. Reducing inequities of access to palliative care services for those in rural and regional communities, those from CALD communities, and for Aboriginal and Torres Strait Islander peoples.
4. Developing a new model of palliative care that provides flexibility in the delivery of care to support patient and family decisions regarding end-of-life care, and makes the best use of the resources available across the system.

A full list of recommendations made in this report is below.

### **Role of the GP in supporting at home palliative care**

1. Review the current HealthPathways for palliative care to ensure they are providing relevant information to GPs on the region's palliative care services and referral pathways. Also ensure that they support GP decision-making regarding care planning for their patients.
2. Develop a communication and engagement program to ensure GPs have a good understanding of palliative care services.
3. Build connections between primary and secondary care and create 'on the job' training opportunities for GPs through joint consultations, case conferencing, and the use of telehealth.
4. Strengthen connections between GPs and community pharmacists to enable more education and support for GPs on palliative medications and prescribing.
5. Develop GPs with a special interest in palliative care across the region to provide support to the wider GP network.
6. Grow nurse practitioner outpatient clinic models to build connections with local GPs, with a focus on early referrals into palliative care services.

## **Building a more connected palliative care system**

- 7.** Enable a shared care plan that is accessible to everyone involved in a patient's care.
- 8.** Develop the GP role to become the central coordinator for the care plan.
- 9.** Build capability and capacity of GPs and nurses to develop robust Advance Care Directives with patients and their families.
- 10.** Ensure information on the care plan is updated proactively and available to anyone visiting the home.

## **Reducing inequities of access to at home palliative care**

- 11.** Build regular use of telehealth into the palliative care service delivery model to enable a more connected system and provide better support to clinicians and patients across the region.
- 12.** Build training in palliative care and use of medication pumps into RACF nurse induction training to ensure equitable access to palliative care within RACFs across the region.
- 13.** Develop accessible information on palliative care services that caters for those from CALD communities and those with disabilities.
- 14.** Implement the greater use of family meetings to discuss the palliative care and end-of-life options available, to develop a care plan, make decisions, and ensure everyone in the family group is well-informed on the services and supports available to them.
- 15.** Provide education and training to the palliative care workforce on the need for religious and cultural assessments for people entering palliative care, and how to reduce barriers to accessing services for people within their communities, including for Aboriginal and Torres Strait Island peoples, people from CALD backgrounds, and people with disabilities.

## **Developing a new model of palliative care**

- 16.** Enable and support a more coordinated, community focused model of palliative care using a broad mix of health professionals (medical, nursing, and allied health), non-clinical support and volunteer organisations by facilitating better connections across the system.
- 17.** Provide education into communities on death as a social process, and the role of palliative care services in supporting this process.
- 18.** Ensure advance care plans are completed for everyone in the community who may benefit from having one in place through targeted training for GPs, nurses, and others within the system.
- 19.** Ensure Advance Care Directives are uploaded to the person's My Health Record.
- 20.** Encourage proactive and coordinated care planning for everyone with a life limiting diagnosis which supports the GP as the centre of the care team and early involvement of other palliative care services.

## **Wentworth Healthcare**

Level 1, Suite 1, Werrington Park Corporate Centre,  
14 Great Western Highway  
Kingswood NSW 2747

T 4708 8100

### **POSTAL ADDRESS**

Wentworth Healthcare,  
Blg BR, Level 1, Suite 1,  
Locked Bag 1797,  
Penrith NSW 2751

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