CARING FOR PEOPLE at END of LIFE

phn
NEPEAN
BLUE MOUNTAINS
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Blue Mountains | Hawkesbury | Lithgow | Penrith

Report for Wentworth Healthcare

provider of the Nepean Blue Mountains Primary Health Network

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Wentworth Healthcare, provider of the Nepean Blue Mountains PHN, is a not-for-profit organisation that works to improve health for the communities of the Blue Mountains, Hawkesbury, Lithgow and Penrith.

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Executive Summary

This report describes the project for Nepean Blue Mountains Primary Health Network (NBMPHN) to explore and understand Advanced Care Planning and key issues facing the provision of End-of-Life Care (EoLC) in the Nepean Blue Mountains region. This work is driven by the significant gap between the services provided to people in their last year of life and the need for such services. A pathway model to support future planning and commissioning of EoLC services for the region was developed.

The aim of this work has been to better understand both the size and nature of EoLC service gaps, why they exist and to make a set of recommendations to guide strategies to improve services or provide new services in the region.

A systems approach was applied to the development of the EoLC pathway model and involved the analysis of data on population, morbidity and underlying cause of death for the Nepean Blue Mountains region. A market analysis and review of service provision was undertaken to understand the nature and extent of current service provision in the region. Both are intended to support the PHN's future EoLC service commissioning.

The analysis identifies, informs and provides guidance for the PHN on the gaps between current service provision and the needs as identified via data analysis and consultation and quantified in the EoLC model. These service gaps and key issues were explored via the use of system maps to identify how the gaps could be closed and service provision addressed according to local need.

Understanding the issues and challenges for EoLC in the region, and development of the model, was built on wide stakeholder consultation via interviews and workshops. Potential interventions were identified and were refined during further stakeholder consultation including a workshop to explore possible solutions and contribute towards a set of recommendations for the co-design and commissioning of EoLC services for the region. Learning from this work and the consultation informs the recommendations for NBMPHN on commissioning of EoLC services. The recommendations fall under 5 key headings:

1. **Initiating End-of-Life Discussions**
2. **Use of Advance Care Plans**
3. **Culturally Appropriate Services**
4. **Provider Capability**
5. **Service and Workforce Review and Development.**

1. INTRODUCTION AND CONTEXT

Synergia was commissioned in June 2017 by the Nepean Blue Mountains Primary Health Network (NBMPHN) to assist the PHN to increase their understanding of Advance Care Plans (ACPs) and their use in current service provision, and to develop a pathway model that could support future planning and commissioning of End-of-Life Care (EoLC) services for the region.

During the time this work was being undertaken, the NBMPHN responded to an Expression of Interest (EOI) from the Department of Health to implement the 'Greater Choice for At Home' palliative care measure. In their response the NBMPHN stated that:

"NBMPHN will use a public health palliative care approach to the implementation of the measure. This approach relies on ethical practice of compassionate communities, bringing together public health; health promotion and community development methodologies to improve access to quality and safe end of life care systems and services."

This EOI had a significant influence on the approach we took to this project, especially regarding the issues analysis. We explored issues not just with current EoLC service provision, but what people saw were going to be important in taking a public health palliative approach built upon the ethical foundation of compassionate communities.

1.1 The Approach

The project has two key components; an EoLC market analysis, a service review of EoLC services for the NBMPHN region, and the development of an EoLC pathway model. The service review focuses on describing current service provision across the region as understood from data collected from service providers. The pathway model focuses on providing an estimate of how many people in the region have EoLC needs, as well as the workforce and cost implications of meeting that need.

Synergia undertook this work in close collaboration with staff from NBMPHN and health professionals from the Local Health District (LHD), aged-care providers, NSW Ambulance and those working in the community. We interviewed 33 people from the region as well as analysing relevant documentation and databases. Two workshops were held to gain input into ideas being developed and to explore some of the key themes emerging out of the interviews and the modelling. In addition, a 'Key Leaders' meeting was held to explore the development of community-based EoLC model based on the concept of compassionate communities.

The service review attempted to obtain a picture of current service provision. It is fair to say that obtaining data on current service provision proved very difficult, so this report is unable to provide a comprehensive overview of the current EoLC market, and services provided for people at the end of their life. It does provide some data on some services but it does not provide a comprehensive description of the quantity and scope of current services. It does however provide a good overview of the data that was available to the project and a platform from which to continue to build this service review via ongoing co-operation with providers to facilitate data sharing.

The development of the pathway model involved the analysis of data on population, morbidly and underlying cause of death for the Nepean Blue Mountains region. This data was incorporated into the model so that estimates of need could be calculated. This data, along with data about illness trajectories, the time spent by each patient group at early, mid-stage and last days of life, and workforce assumptions were discussed with a number of senior health professionals. Descriptions of the three workforce types, ‘generic’, ‘enhanced’ and ‘specialist’ were also reviewed, so that the time required by each workforce type to care for EoLC patients at key points along the EoLC pathway could be quantified.

This report provides, as background, 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 EoLC services in Nepean Blue Mountains to support the PHN with future EoLC service planning, commissioning and continuous quality improvement of existing EoLC services.

2. POPULATION HEALTH PROFILE OF THE NEPEAN BLUE MOUNTAINS REGION

2.1 Overview

The Nepean Blue Mountains region spans 9,123 square kilometres and aligns with the Nepean Blue Mountains Local Health District. The region had a population of 358,652 as of 2016[1]. The population is projected to grow by 17.4% between 2016 and 2025 (NSW state average is 15.0%), taking the total number of residents living in the region to 421,003[2].

2.2 LGA Regions

The Nepean Blue Mountains region has four Local Government Areas (LGA): Blue Mountains, Hawkesbury, Lithgow, and Penrith. Table 1 outlines each LGA's population size as of 2016, as well as expected population growth.

Table 1: Resident Population, 2016

LGA	Population	Estimated Population 2025	Estimated Growth
Blue Mountains	76,904	89,416	16.3%
Hawkesbury	64,592	79,024	22.3%
Lithgow	21,090	22,578	7.06%
Penrith	196,066	229,985	17.3%

2.3 Age

The population of those aged over 65 years in the Nepean Blue Mountains region is set to increase by 31.2% between 2016 – 2025, which is higher than the state average of 29.9%. Penrith will experience the highest growth in older persons by 2025.

Table 2 and Figure 1 outline population size[3] and expected growth[4] for persons aged 65+ for each LGA, highlighting regions with an older population (eg. Lithgow) and regions with an expected ageing population (eg. Penrith).

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[1] Australian Bureau of Statistics, 2016 Census.

[2] Estimated Resident Population, PHIDU Social Health Atlas Data by PHN Published: August 2017.

[3] Australian Bureau of Statistics, 2016 Census.

[4] Estimated Resident Population, PHIDU Social Health Atlas Data by PHN Published: August 2017.

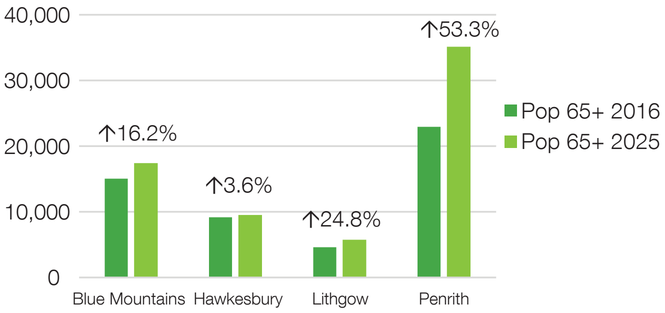
Table 2: Population aged 65+

LGA	Pop 65+ 2016	% of pop aged 65+	Pop 65+ 2025
Blue Mountains	15,027	19.5%	17,465
Hawkesbury	9,217	14.3%	9,553
Lithgow	4,641	22.0%	5,791
Penrith	22,920	11.7%	35,136

This projected growth in the older population for the region will increase the demand on local health services and impact on the required workforce needed to successfully manage demand in all areas of health care, but particularly aged care and EoLC services.

This is a situation NBMPHN, 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.

Figure 1: Expected Growth Population 65+



The current age profile of the region is very similar to the current NSW age profile (Figure 2). Of note is the differences between this region and NSW in 2025 for the 25-44, 45-64 and 65 years and older age groups. These are projected to be smaller as a percentage of the population compared to NSW.

Figure 3 outlines the expected population growth for each age group between 2016 and 2025 in the Nepean Blue Mountains and NSW. Nepean Blue Mountains tracks similar growth compared to the state average for younger (0-14) and older (65+) age groups.

However, Nepean Blue Mountains expects significantly larger growth than NSW for persons aged 15-24 and 45-64, and significantly less growth for persons aged 25-44. The 65+ age group trends closely to that of NSW.

Figure 2: Percentage of the population by age from 2016 to 2025 for Nepean Blue Mountains and NSW

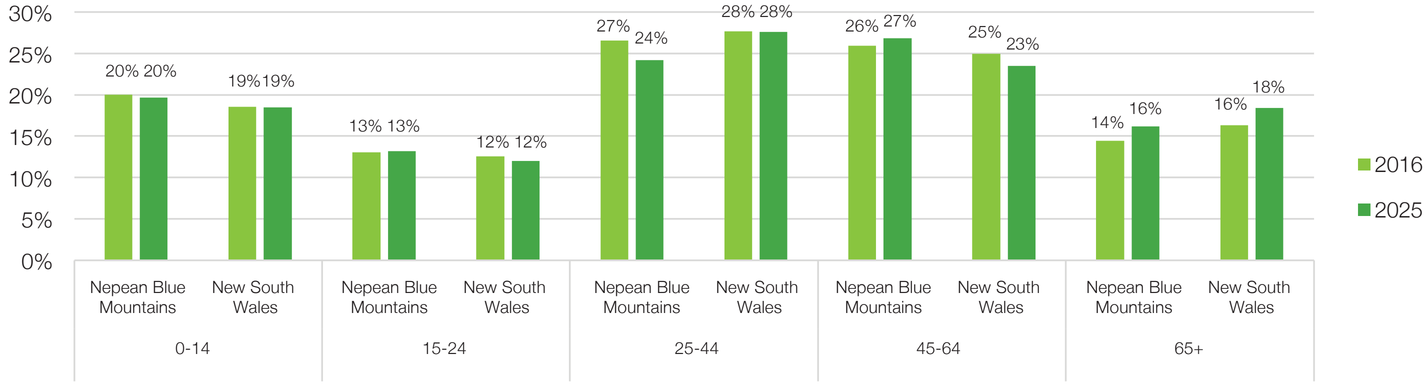
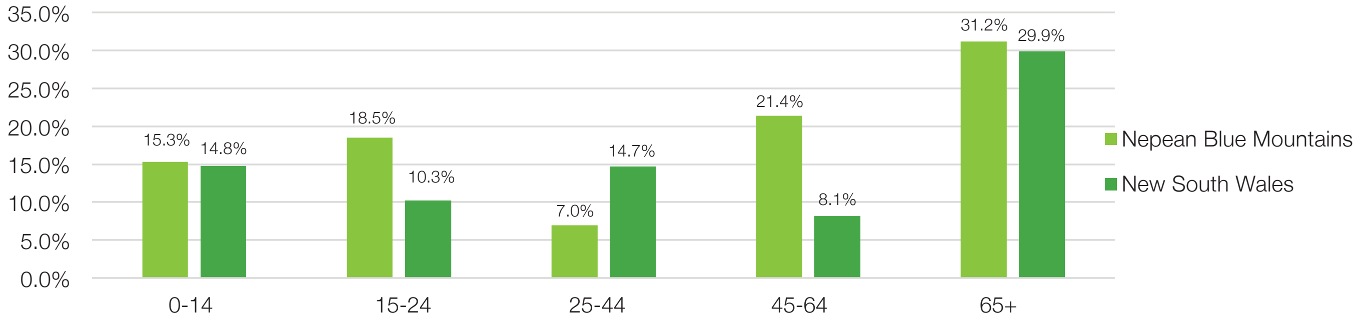


Figure 3: Expected population growth by age from 2016 to 2025 for Nepean Blue Mountains and NSW



2.4 Ethnicity

Table 3 outlines the number and percentage of people from culturally and linguistically diverse communities and the number of Aboriginal and Torres Strait Islander people based on 2016 Census data. The region has a large Aboriginal population residing in the area (above the state average), as well as a culturally and linguistically diverse population. Three quarters of the Nepean Blue Mountains population (75.6%) were born in Australia, compared with 65.6% in NSW, with a far smaller percentage of people born overseas in a predominantly Non-English speaking country or with poor English skills.

Table 3: Comparison of Culturally and Linguistically Diverse Communities

Community Type	Nepean Blue Mountains Population	% of Nepean Blue Mountains Population	% of New South Wales Population
Born in Australia	271,243	75.6	65.6
Aboriginal and Torres Strait Islander Persons	13,166	3.7	2.9
% born overseas in English speaking countries	26,191	7.3	6.7
% Born in non-English speaking countries	39,065	10.9	21.0
% Born Overseas poor English	3,204	1.0	3.8

Table 4 provides information on the number of people by LGA who identified as Aboriginal and Torres Strait Islander in 2011 or who are from culturally and linguistically diverse communities.

Table 4: Culturally and Linguistically Diverse Communities by LGA

Community Type	Blue Mountains	Hawkesbury	Lithgow	Penrith
% Born in Australia	78.0	82.2	84.8	74.3
% Aboriginal and Torres Strait Islander Persons	2.4	3.7	5.7	3.9
% born overseas in English speaking countries	10.3	7.0	4.9	7.5
% born in non-English speaking countries	6.3	5.5	4.1	13.3
% with poor English	0.3	0.5	0.3	1.4

The LGA analysis shows a relatively high number of Aboriginal and Torres Strait Islander people[5] in Lithgow which may result from the population within the Lithgow Correctional Centre. Penrith has the highest number of people born in a non-English speaking country and correspondingly the highest number of people with poor English.

It is evident that the region has a diverse population, including Aboriginal people and people born outside Australia. These population groups generally have significantly poorer health outcomes compared to other population groups, which indicates a need for additional and appropriately targeted health services. This could encompass training for healthcare providers to ensure culturally safe services are available to meet the needs of this population group and address their poor health outcomes, including training in culturally appropriate Advanced Care Planning and provision of EoLC services.

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[5] From here on, where the term Aboriginal is used throughout this report, it refers to Aboriginal and Torres Strait Islander peoples.

2.5 Morbidity

The rates of avoidable death are shown below (Figure 4) and the median life expectancy (Figure 5). There is some variation in avoidable deaths between LGA's and life expectancy, for both measures Lithgow and Penrith have fared poorer compared to other LGAs in Nepean Blue Mountains, and compared to the state. Avoidable deaths include causes such as avoidable mortality by cancer, diabetes, suicide or transport incidents. Blue Mountains and Hawkesbury have lower rates of avoidable deaths compared to other LGA's and the state average.

Figure 4: Avoidable Deaths persons under 75 (ASR per 100,000) 2010-2014

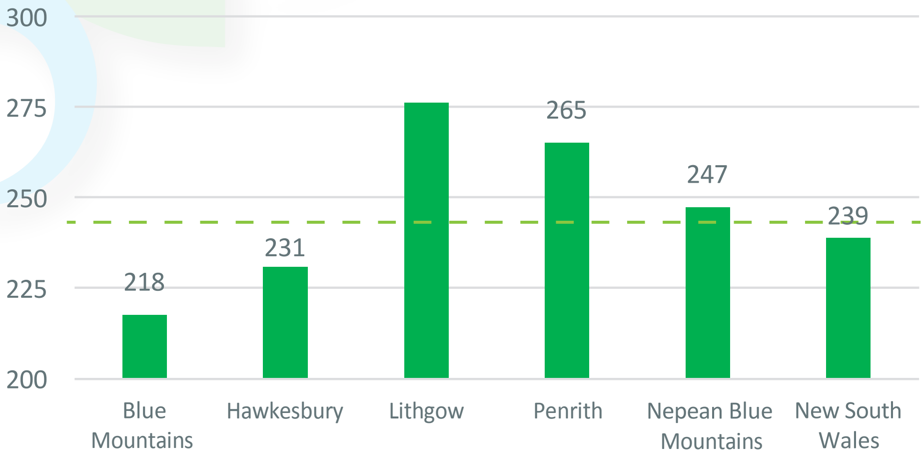

Figure 5: Median Age of Death (Years) 2010-2014

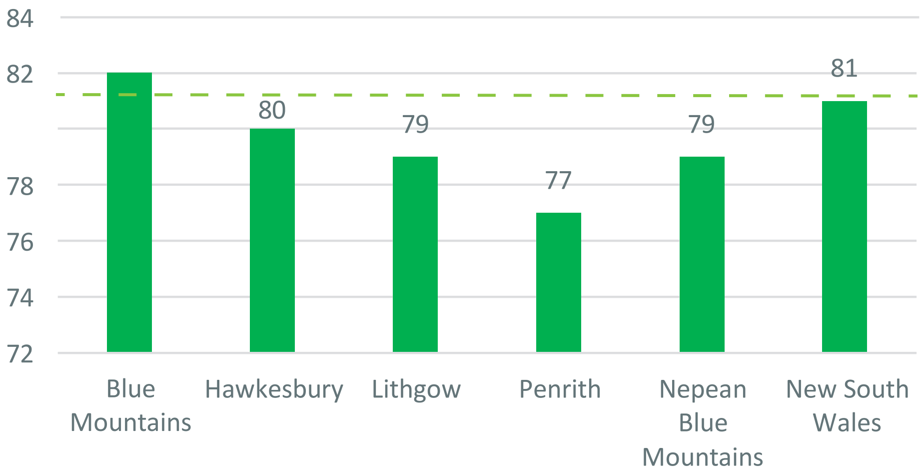

Table 5 outlines cause of death by region for cancer, circulatory Nepean Blue Mountains generally fares similarly to NSW. However, for all death types, Penrith and Lithgow tend to fare worse, and Blue Mountains and Hawkesbury notably better.

Table 5: Cause of death by type and region (0-74 years)

Region	Deaths from cancer		Deaths from endocrine, nutritional and metabolic diseases		Deaths from circulatory system diseases	
	No.	ASR per 100,000	No.	ASR per 100,000	No.	ASR per 100,000
Blue Mountains	413	92.6	14	3.2	188	42.7
Hawkesbury	263	90.0	12	4.2	138	47.3
Lithgow	131	105.8	9	7.2	68	55.2
Penrith	842	108.3	46	6.0	444	57.5
Nepean Blue Mountains	1,648	100.6	81	5.0	839	51.5
New South Wales	35,600	101.9	1,837	5.2	16,121	46.1

3. LOCAL SERVICE PROVISION

3.1 Introduction

A market analysis of current EoLC service provision was conducted to provide information to NBMPHN for future service planning and to support the PHNs commissioning framework, The focus was a review of service level data for the region.

A data collection exercise was completed where service providers across the region were asked for information specifically related to:

- Who is currently providing services for people in their last year of life? These services may, or may not, be delivered under the title of "Palliative Care" and may be provided directly or sub-contracted
- What volume of patients are they caring for?
- Any available information about these patients – especially age and underlying condition
- The nature and source of the contract i.e. who is paying for or funding these services.

3.2 Local service provision data

Data was provided by the following service providers in the region:

- **South Western Sydney Local Health District –** for The Palliative Care Home Support Packages (PEACH) Program
- **Anglicare –** for care in Residential Aged Care Facilities and the community
- **Mid Mountains Neighbourhood Centre –** for the Blue Mountains Palliative Support Service
- **Nepean Blue Mountains Local Health District from the Palliative Care Outcomes Collaboration –** for inpatient palliative care services at Nepean Hospital.
- **Nepean Blue Mountains Local Health District Community Nursing** in Penrith and Blue Mountains LGA's.

The PEACH program[6] provides care packages to palliative care clients in selected Local Health Districts (LHDs) within NSW and is sub-contracted to Silver Chain Group. This program aims to support palliative care clients in the last days of their life in their own home. The Program consists of personalised packages of care of short term (up to seven days) duration to support individuals at the end of their life.

Anglicare's Palliative Care Team provides support to Anglicare homes and community services, the team links with community services as required for more complex care of Residents.

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[6] https://www.swslhd.health.nsw.gov.au/peach/pdf/brochure/slhd/English.pdf and www.swslhd.health.nsw.gov.au/peach/

The Blue Mountains Palliative Support Service is located at the Lawson Community Centre and services the area from Emu Plains to Lithgow. The service provides volunteers to support people who are terminally ill in their home, in local hospitals or (for limited periods) in aged care facilities.

Finally, the Lemongrove Community Health Facility in Penrith and Lawson Community Health Facility in Blue Mountains provide palliative care predominately in people's homes. Table 6 describes the data collected from these community-based services.

Data was requested from a range of other service providers in the region but could not be obtained in the timeframe of the project.

Table 6: Data collected from EoLC service providers

PEACH Program	Anglicare	Blue Mountains Palliative Support Service	Nepean Blue Mountains Local Health District – Hospitals	Nepean Blue Mountains Community Nursing
July 16 – June 17: No. of referrals, completed packages, no. of individuals receiving packages and no. deaths at home	Jan 16 – Oct 17: Summary of patient demographics and reason for referral to service	Annual Activity Report 2016 – 17: Volunteer hours provided Volunteer workforce Hours of service provision in the community and in inpatient facility	July – Dec 2016: Patients, Episodes and Phases[7] Patient Outcomes, Diagnosis, Symptoms, Phase, Gender, Episode End, Phases per episode	Nov 2017: Number of current clients, number of malignant and non-malignant clients, average length of stay
April – June 17: No. of referrals, completed packages, no. of individuals receiving packages and no. deaths at home			Jan – June 2017: Patients, Episodes and Phases Patient Outcomes, Diagnosis, Symptoms, Phase, Gender, Episode End, Phases per episode	Jun – Nov 2017: Number of persons discharged by death Reasons for discharge from service
Oct 16 – Sep 17: No. of referrals, completed packages, individuals and deaths at home. Packages completed by Quarter by LHD. No. of Open Packages Diagnostic Groups, PEACH separations, Hospital Referrals				

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[7] The palliative care phase identifies a clinically meaningful period in a patient's condition. The palliative care phase is determined by a holistic clinical assessment which considers the needs of the patients and their family and carers.

3.3 Market Analysis

The data provided to the project by service providers in the region does not support a robust or detailed market analysis of current EoLC service provision. The data obtained from service providers (see above) is disparate, inconsistent and covers variable timeframes of EoLC service activity. For example, some service provision data was available for periods of 12 months, other data was only available for 3 months of service provision. Another key variable that is inconsistent is data describing number or people cared for. Some providers provided actual numbers of people receiving EoLC service, while others only provided total hours of service provision. There was scant patient demographic or clinical data provided, making any analysis of appropriateness of service provision to population need very difficult.

Consequently, there is insufficient data to assess levels of EoLC service provision relative to need or service gaps in the region. As a very high-level summary, we would say that EoLC services are being provided by a range of public, private and NGO providers and in inpatient facilities, Residential Aged Care Facilities (RACFs), patient's homes and other community settings such as Community Centres.

Eligibility and referral processes are variable across services, potentially indicating inequity of access to some EoLC services for patients. The PEACH program illustrates this, whereby patients must be known to the LHD Palliative Care Service. Referrals may also be accepted from GPs, however this will usually be made via the LHD service. In contrast, the Blue Mountains Palliative Support Service is provided to anyone with a life limiting illness. Their family and carers living in the Blue Mountains and clients are referred by the community nurses, general practitioners and community services. Hence, clients do not need to be known by the LHD service which supports a more community-based service approach. Conversely variation in referral processes and eligibility contributes towards demand management of limited resources such as funding and workforce.

Further, there is variation in service provision across metropolitan, regional and rural areas of Nepean Blue Mountains. An example is where people face the challenge of a greater distance to travel to receive specialist care in hospital[8]. Lithgow residents currently cannot access palliative care at the local hospital. Instead palliative patients are admitted to Blue Mountains, Hawkesbury, Nepean or Springwood Hospitals and, despite the distance from a hospital most Lithgow residents receive EoLC services in hospital rather than the community. EoLC service available locally in Lithgow include the PEACH program and the Blue Mountains Palliative Support Service which expanded to Lithgow in 2013.

[8] http://www.lithgowmercury.com.au/story/4733126/palliative-care- boost-figures/

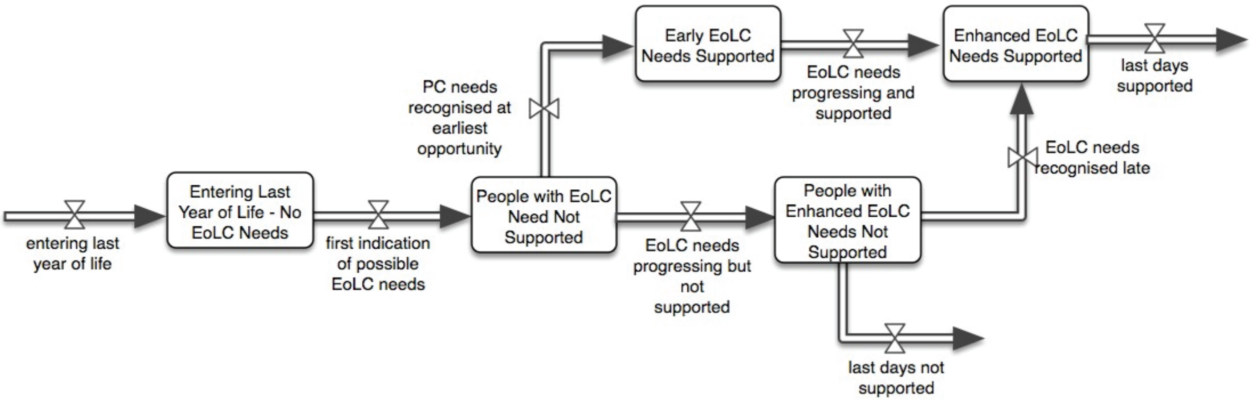
4. SIZE AND NATURE OF THE NEED FOR END-OF-LIFE CARE IN THE REGION

4.1 Model Overview

As with the data on current service provision, data on the level of need for EoLC services in the Nepean Blue Mountains region is either non-existent, unavailable from providers, or anecdotal. Without that data the PHN is left to make inferences and estimates from the regional population health data. A key task of this project has been, therefore, to build a model that provides a more robust estimate of this need within the Nepean Blue Mountains region, using a range of national, state and local data. Figure 6 provides a high-level view of the model structure.

The model provides a structure for tracking people through their last year of life, by age, gender, local government area and the primary underlying cause of death. Morbidity data was used to estimate those entering their last year of life and 'Causes of Death' data was used to estimate those, in their last year of life who could benefit from EoLC.

Figure 6: High-Level Overview of Model Structure



Data provided by the Australian Bureau of Statistics was used to estimate the population growth in the region[9] and the mortality rates, by age, within each of the four local government areas (LGA's)[10]. This provided the baseline data for the estimates used in the model. Those deaths were then categorised by their age and primary cause of death, as specified in the ICD10 codes[11].

This analysis provided us with estimates of the number of people entering their last year of life, by age and by primary cause of death. Current population and population projections were then incorporated into the model to provide estimates of the number of people entering their last year of life in the Nepean Blue Mountains region for the next 15 years.

The model runs for 180 months (15 years) from 2015 to 2030. Thus month 0 is 2015, month 24 is 2017, month 120 is 2025 and month 180 is 2030.

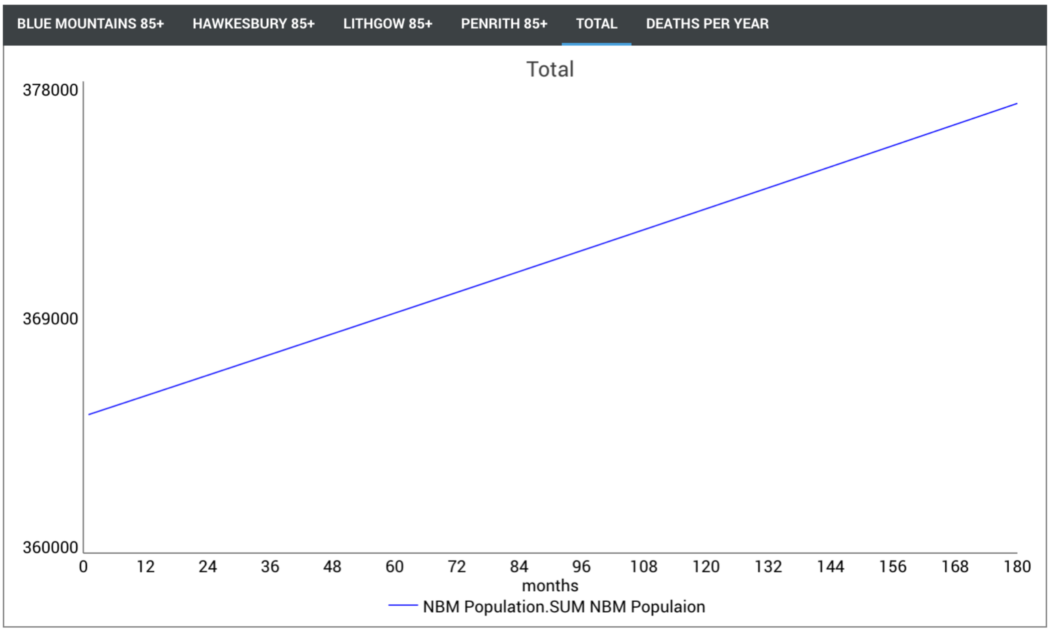
The model can be accessed on the following link:

https://exchange.iseesystems.com/public/davidrees/nbmphnEoLC

4.2 Population Baselines

The base line population projection is shown below in Figure 7.

Figure 7: NBM Population Projection



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[9] Australian Bureau of Statistics: Regional Population Growth, Australia. Released 30 March 2016.

[10] AIHW (Australian Institute of Health and Welfare) 2017. MORT (Mortality Over Regions and Time) books: Local Government Area (LGA), 2010–2014. Canberra: AIHW.

[11] Australian Bureau of Statistics: 3303.0 Causes of Death, New South Wales, 2015. Released 28 September 2016.

The graph shows that the population in Nepean Blue Mountains region was just over 365,000 in 2015 and estimated to grow to 377,000 by 2030. Of more significance however is the nature of that growth, with the population under the age of 65 expected to grow by under 2 percent over the next 15 years, while the population growth of those over 85 is expected to grow by over 12 percent.

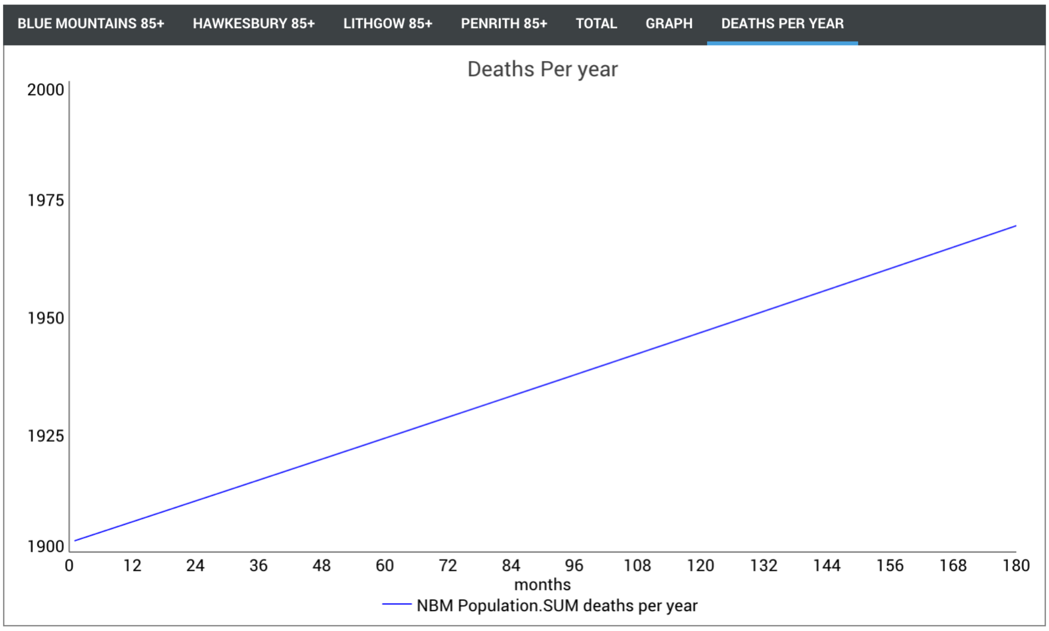
> The fact that the Nepean Blue Mountains region will see its greatest growth amongst the older population within the poorest LGA is significant for the future planning of palliative and EoLC for the NBMPHN

There is also significant regional variation with the population of those 0 to 64 expected to decrease very slightly in Lithgow, while expected to grow in Penrith. The fact that the Nepean Blue Mountains region will see its greatest growth amongst the older population within the poorest LGA is significant for the future planning of palliative and EoLC care for the NBMPHN.

4.3 People Entering Last Year of Life

Figure 8 shows the estimated number of deaths in the Nepean Blue Mountains region rising from around 1,900 in 2015 to just under 2,000 by 2030.

Figure 8: Deaths per Year



Not all people are however going to need EoLC in their last year of life. Various methods have been used to provide estimates and the method used in this report is based on the work by Lucas Morin et al (2016)12. This is a recent paper that builds on earlier work and provides a comprehensive description of how to use the ICD10 codes to develop the estimates. Reviewing the changing patterns of mortality this paper notes that.:

"most deaths occur after a period of physical, psychological, and cognitive decline, which negatively impacts last days, weeks, months, and sometimes even years of life. People who face a trajectory of serious and life-limiting illness, therefore, require adequate care at the end of life, focusing not only on the disease itself but also on the management of physical symptoms, the relief of psychological distress, and the support of family caregivers"

It is important, therefore, to not only provide estimates of the numbers in the region who die each year, but estimates of those dying of conditions that would indicate the need for EoLC services, the age distribution of these people and the different patterns that lie behind these needs (i.e. their likely trajectory in their last year of life). In line with other work in the field we have followed accepted practice and allocated people who would benefit from EoLC in their last year of life into three categories:

1. **Short period of evident decline**, typically cancer patients
2. **Periods of long-term limitations** with intermittent acute episodes, typically associated with long-term conditions such as cardiovascular disease, respiratory disease and diabetes
3. **Prolonged dwindling**, characteristic of older people suffering from neurodegenerative disorders, and generalised frailty due to progressive loss of physical and cognitive functioning.

4.4 Estimates of Need for EoLC in the Nepean Blue Mountains region

Applying the method outlined in Morin et al's paper to the ICD10 codes describing the causes of deaths in the Nepean Blue Mountains region it is estimated that 72 percent of people entering their last year of life could benefit from EoLC.

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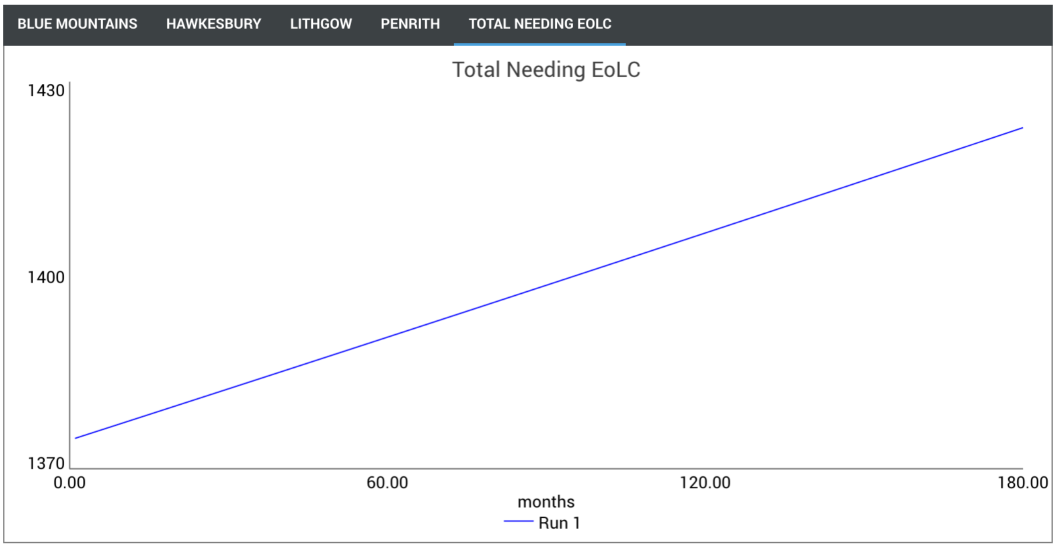
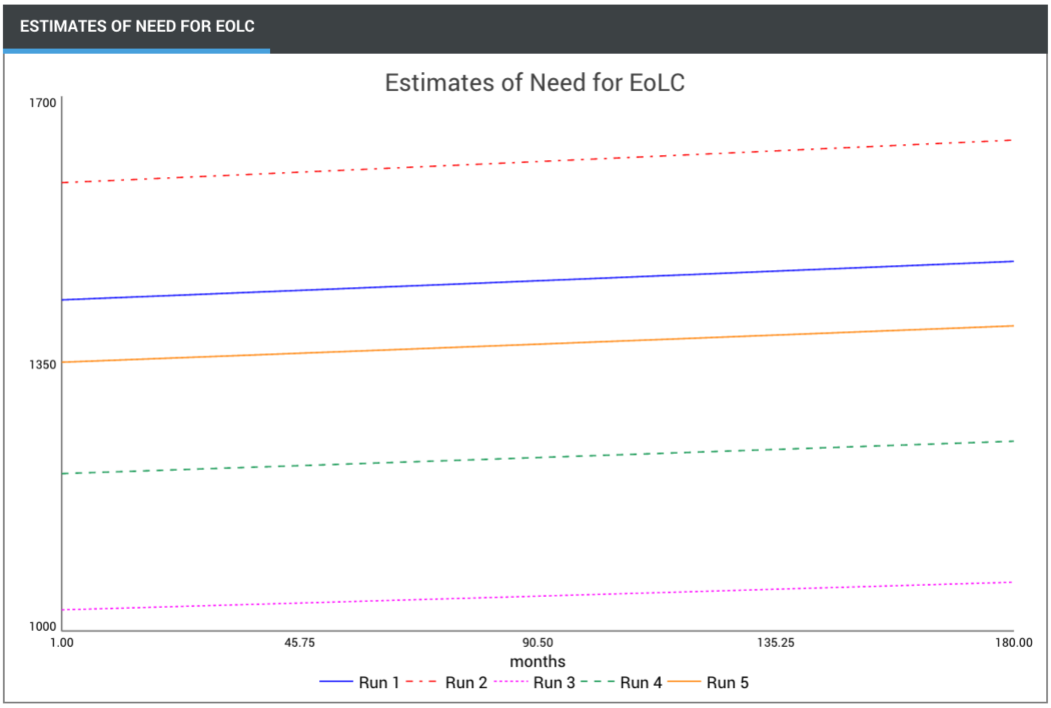
[12] Morin, L., et al (2016). Estimating the need for palliative care at the population level: A cross-national study in 12 countries. Palliative Medicine

Figure 9: People Needing EoLC in the Nepean Blue Mountains Region



Using these calculations in the model, Figure 9 provides an estimate of the number of people requiring EoLC in the Nepean Blue Mountains region over the next 15 years. As Figure 9 shows this number is estimated to grow from 1,370 to over 1,400 per year. To look at the potential range a further five simulation runs were done to provide estimates given an average of 72 percent (as used in Figure 9) and a standard deviation of 10. This gives us estimates of between 1,030 and 1,590 in 2015 and between 1,060 and 1,640 in 2030.

Figure 10: Estimates of Need for EoLC (sensitivity analysis)



As noted above, we do not know the full scope of services being currently provided for people at the end of their life however, from feedback provided by health professionals in both workshops, these estimates are much larger than those they believe are currently receiving good care at the end of their life. So, while we cannot provide an exact estimate of the service gap it is likely to be significant.

Broken down by trajectory, using the ‘cause of death’ data from the Australian Bureau of Statistics13, approximately 41 percent of these people would be cancer patients experiencing a short period of decline, 45 percent would be patients with long-term conditions, experiencing periods of long-term limitations with intermittent acute episodes and 14 percent would be older patients suffering from neurodegenerative disorders, and generalised frailty due to progressive loss of physical and cognitive functioning.

The web model [see link in section 4.1] provides the ability to explore a wider range of scenarios than those discussed above, as the data is broken down by age, gender, LGA and underlying condition. It is possible therefore, to obtain estimates of, for example, the number of people 85+ entering their last year of life, living in Penrith, whose underlying condition is characterised by periods of long-term limitations with intermittent acute episodes. That is, people who have one more long-term conditions such as renal damage or failure.

These more detailed scenarios can be used to support needs analysis as well as future commissioning.

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[13] Australian Bureau of Statistics: 3303.0 Causes of Death, New South Wales, 2015. Released 28 September 2016.

5. KEY ISSUES IN PALLIATIVE AND END-OF-LIFE CARE

The approach to localising the EoLC model was built on wide stakeholder consultation during which we interviewed a wide range of people involved in Palliative and EoLC from throughout the region. This included people from community and primary health services, hospital services, not for profit providers as well as people working in policy, management and patient advocacy roles. In total 33 people were interviewed. 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 interviewees perspectives on:

- key issues being faced by palliative and EoLC in the Nepean Blue Mountains region
- the underlying causes of those issues, and
- the consequences of the issues been addressed successfully or not.

The issues raised in the interviews were captured and then analysed using cognitive mapping,[14] which is a method of exploring links between ideas. Specifically, it maps the thinking behind the three questions noted above, namely what are the issues, 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 11) the idea '51 lack of ability to recognise the dying'[15] influences '1 EoLC discussions often start at times of crisis'. Simply, this is saying that because there is often a lack of ability to recognise when someone is dying, the discussions about EoLC often only start when there is a crisis, rather than when there are initial signs that someone is entering the last phase of their life. The ideas at the bottom of the map are key drivers, and indicate potential areas of interventions. Those at the top are potential consequences, some desirable, some not. They provide potential goals to be strived for, and risks that need to be avoided.

In addition, the cognitive maps, and the issues that emerged from them, were discussed during workshops held on 18 September and 26 October 2017. These discussions focused on the opportunities (what potential positive consequences could arise from successfully addressing the issue), the risks (what potential negative consequences could arise from not addressing the issues successfully, and the potential actions that could be to undertaken to address the issues successfully.

The following sections describe the key issues that emerged during these interviews and the subsequent workshop discussions.

[14] 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.

[15] NOTE: the numbers associate with each idea are simply attached by the computer when the idea is entered. They are simply used by the computer to track ideas in the database. They do not indicate any value or priority given to any specific idea.

5.1 Initiating End-of-Life Discussions

The following cognitive map describes the issues revolving around difficulties in initiating end-of-life discussions.

5.1.1 End-of-Life Discussions: Mapping the Issue

Figure 11 is a cognitive map that illustrates the connections between ideas that relate to initiating end-of-life discussions.

At the bottom of the map there are a number of drivers affecting the initiation of end-of-life discussions. One relates to training of general practitioners (GPs) (77), another highlights the fact that it is often junior staff that the patient sees if they present to hospital with an acute episode (2). The third refers to the lack of preparation many carers have to provide EoLC (83). The consequences of initiating EoLC discussions at a time of crisis is distress for the patient (4), hospital staff responding to the immediate acute symptoms with little if any understanding of the patients end-of-life needs (46 and 43). This is often made worse by the fact that the information the clinician is having to refer to is often incorrect (42). This lack of understanding contributes to further patient suffering (49) and often increased use of unnecessary resources (37).

5.1.2 End-of-Life Discussions: Designing Interventions

The logic of the map highlights some potential areas for intervention. Potential interventions to consider are:

4. Training in EoLC for GPs and other primary and community care health professionals.

5. Training, education and/or support for carers

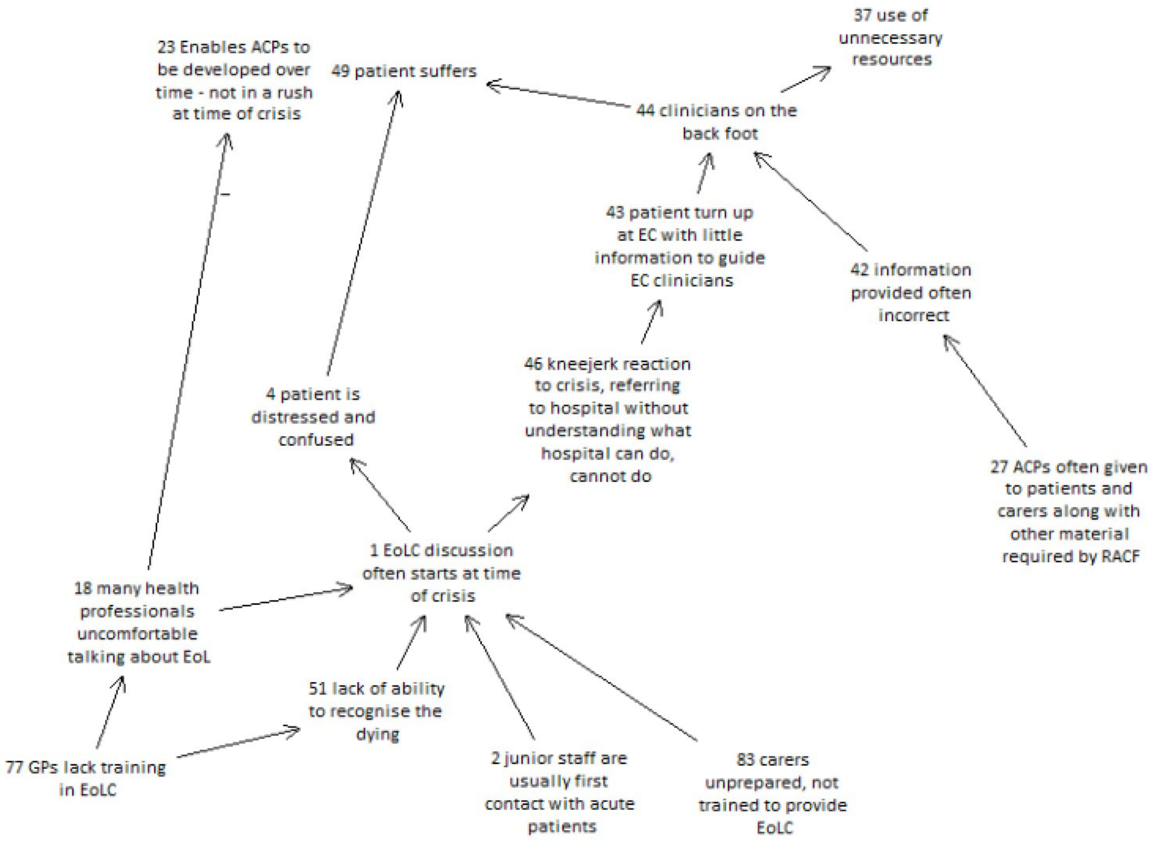
6. Establishment of ‘flags’ and protocols to ensure that patients with EoLC needs are immediately recognised when they arrive in the emergency department (ED) and, wherever possible, are seen by a more experienced clinician.

5.1.3 End-of-Life Discussions: Goals

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

1. Improved and more timely information available to emergency department (ED) clinicians seeing EoLC patients
2. Number of ‘after hours’ referrals from RACFs to ED

Figure 11: Initiating End-of-Life Discussions



5.1.4 Workshop Outputs: End-of-Life Discussions

If these were undertaken in an appropriate and timely manner then not only would care be improved for patients and their families, but there would be a decrease in hospital admissions and ambulance callouts as well as decreased numbers dying in ED departments and places they did not prefer.

To address this issue successfully workshop participants discussed a number of potential actions including:

1. Assist in 'normalising' death through initiatives such as 'death cafes and 'Dying to Know Days'.
2. Recognise that care networks are much bigger than health and begin by identifying current informal care networks that already exist.
3. Support GPs and other primary care providers, including those in RACFs to have end-of-life conversations, for example through 'relative days' at the RACF.
4. Establish a 'Key Leaders Group' to become the focal point and driver of many of the recommendations discussed in this report.

5.2 Use of Advance Care Plans

Figure 12 is a cognitive map that illustrates the connections between ideas that relate to the use of Advance Care Plans (ACPs).

5.2.1 Advance Care Plans: Mapping The Issues

At the bottom of the map there are a number of drivers affecting the use of ACPs. A number of these (5, 25, 17 and 26) highlight the lack of communication and cooperation across agencies, resulting in inconsistent design and use of ACPs. Idea numbers 27 and 41 also highlight that the ACP is often provided to the patient by someone not skilled or experienced enough to discuss the issues that the document may raise for the patient and/or their carers. As a consequence discussions about end-of-life are often late, handled poorly and based on incorrect information.

5.2.2 Advance Care Plans: Designing Interventions

The logic of the map highlights some potential areas for intervention. Potential interventions to consider are:

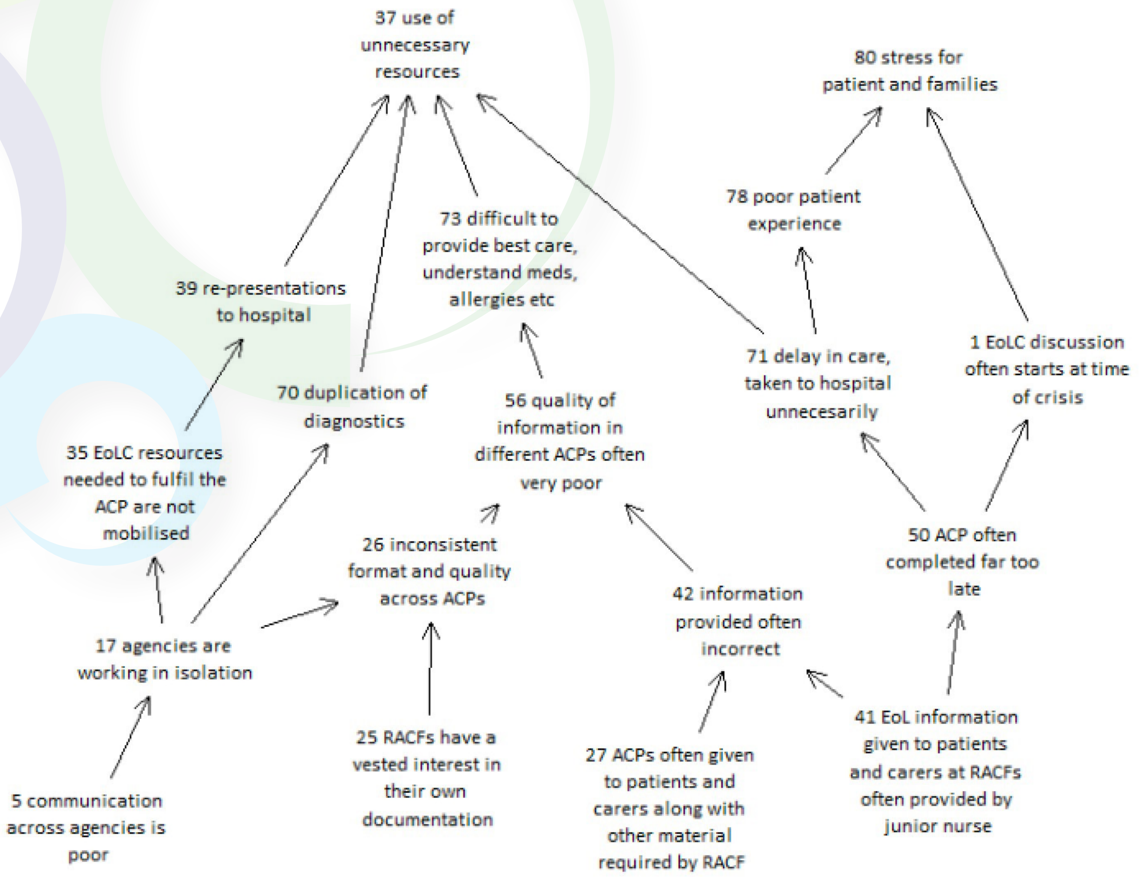
1. Establishment of a set of core principles that should guide the design and use of ACPs, including protocols for how it should be presented to patients and/or their carers.
2. Development of education material and workshops to explain the primary role of ACPs to support the initiation and development of appropriate and timely end-of-life conversations, and the mobilisation of the resources needed to support the patient.
3. Facilitate conversations amongst RACFs to support the adoption of points 1 and 2 above.

5.2.3 Advance Care Plans: Goals

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

1. Reduction in the duplication of hospital-based diagnostic resources.
2. Reduction in the number of end-of-life patients who die within 48 hours of being admitted to hospital.
3. Increase in the number of people who die in the place they have stated in their ACP as their preference.
4. Increase in the use of ‘care networks’ to support people in their last year of life.

Figure 12: Use of Advance Care Plans



5.2.4 Workshop Outputs: Use of Advance Care Plans

Workshop participants considered that appropriate and timely use of ACPs would ensure that people would have their wishes and preferences for end-of-life recorded and respected, potentially improving the dying experience for patients and their families and carers. It would support and facilitate better care, decision-making and more realistic planning, as well as help families and carers manage the dying experience more positively. When it either not completed, or done poorly it can lead to inappropriate and unwanted treatment and hospital admissions. It also decreases the accountability for both the care and the outcomes of that care during the end-of-life period and after death.

To facilitate the appropriate and timely use of ACPs, workshop participants recommended that;

1. Work is undertaken to clarify the purpose of ACPs (to support conversations and mobilisation of resources) as well as key terminology used within them.
2. Explore ways of improving the accessibility of ACP within the medical health record.
3. Review samples of current ACPs and use those to develop guidelines on their design and use.

5.3 Culturally Appropriate Services

Figure 13 is cognitive map that illustrates the connections between ideas that relate to the provision of culturally appropriate services.

5.3.1 Culturally Appropriate Services: Mapping The Issues

While the map focuses on the Aboriginal population, the ideas relate to many of the different cultural groups in the Nepean Blue Mountains region.

At the bottom of the map there are four key drivers affecting the delivery of culturally appropriate services. Idea 118 highlights the lack of Aboriginal, and other staff with different cultural backgrounds, while 115 highlights the tendency to have only one idea of what constitutes good end-of-life services and 112 points out that there is little funding to support series that are focused on specific cultural groups. 113 highlights that different cultural groups have quite different attitudes and cultural norms surrounding death and dying, so understanding what people need, also requires that providers have that cultural understanding.

Consequently, many Aboriginal people, and people from other cultural backgrounds do not die in their culturally preferred way, creating stress for them and their family and carers. In addition, the lack of culturally appropriate services, with their attendant issues for the patient and the families contributes to unnecessary ambulance callouts and subsequent hospitalisations.

5.3.2 Culturally Appropriate Services: Designing Interventions

The logic of the map highlights some potential areas for intervention. Potential interventions to consider are:

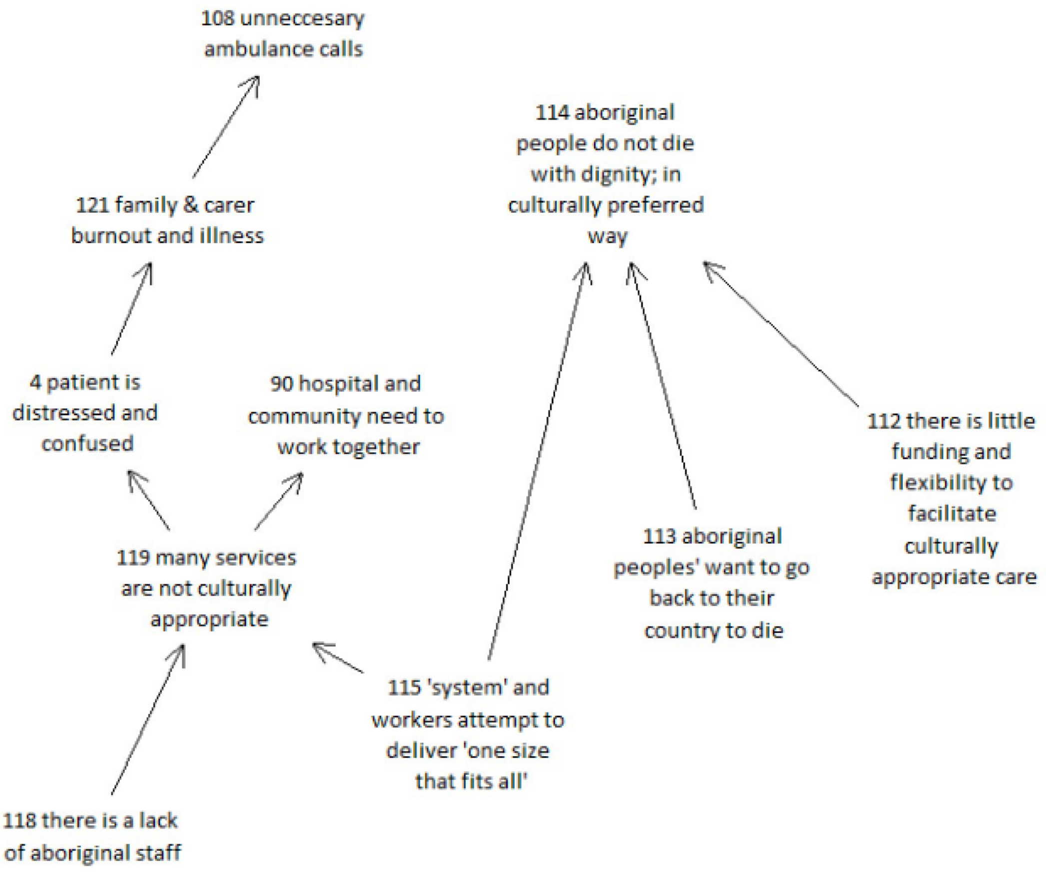
1. Provide resources that support the recruitment and retention of Aboriginal staff and other staff that represent the cultural mix of the Nepean Blue Mountains region. Thought may also need to be given to the development and/or provision of training programmes to support the development of such people if they do not possess the skills needed for such positions.
2. Work closely with the Aboriginal Health Unit and the Multicultural Health Unit at the Local Health District (LHD) to explore cooperative approaches to the recruitment and development of a more diverse workforce providing EoLC.
3. Work with the Aboriginal Liaison officer to promote, and design if required, in-house programmes to improve the cultural literacy of key PHN staff.

5.3.3 Culturally Appropriate Services: Goals

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

1. An increase in the number of aboriginal, and other culturally appropriate staff, providing end-of-life services.
2. An increase in the amount of funding to support culturally appropriate services.
3. An increase in the number of Aboriginal people, and people from other cultural minority groups, who express satisfaction with the end-of-life services they received for the loved one.

Figure 13: Culturally appropriate services



5.3.4 Workshop Outputs: Culturally Appropriate Services

In addition to an improved experience at end-of-life, reducing stress and discomfort for the patient and their carers, workshop participants felt that the provision of services that were more culturally appropriate would build trust within the community and provide more equitable access to services. The provision of such services would also help to attract providers from more diverse cultural backgrounds. The poor provision of such services was seen to contribute to not only distress and very poor end-of-life experiences but also increased hospital admissions.

The primary recommendation of the workshop participants was to establish a CALD resource co-ordinator, who would provide a navigation role, assisting patients and their families link with the people and services most appropriate for their needs.

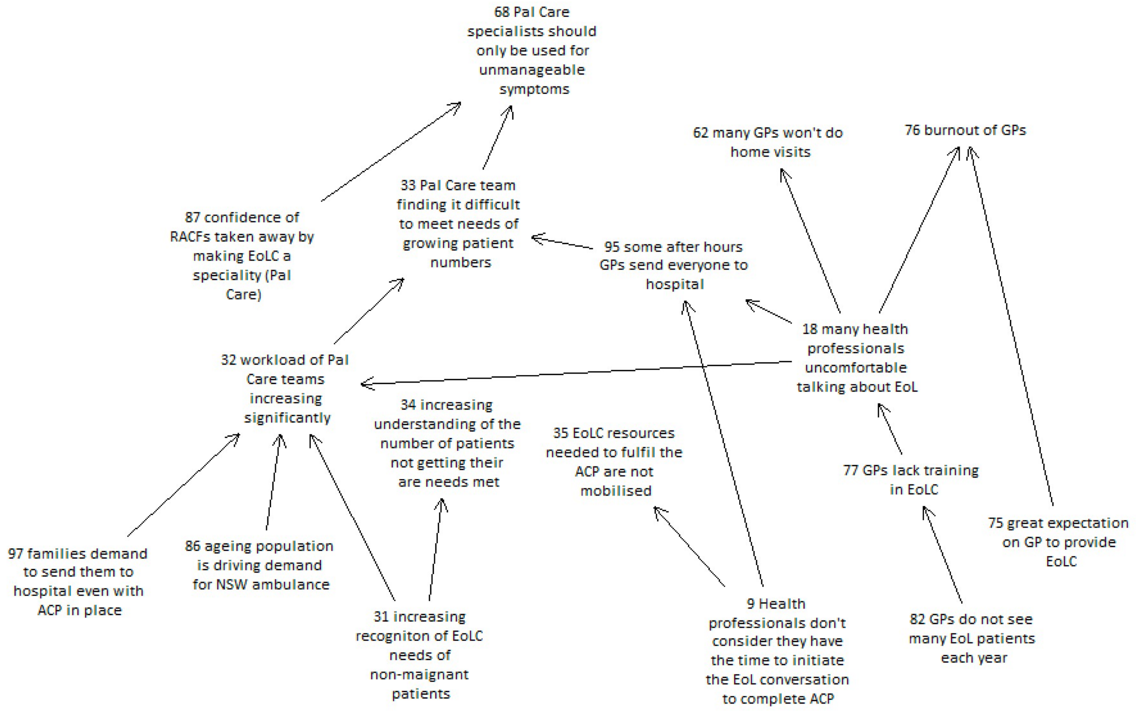
5.4 Provider Capability

The cognitive map on the following page (Figure 12) illustrates the connections between ideas that relate to the capability of those providing end-of-life services.

5.4.1 Provider Capability: Mapping The Issues

Idea 31 acknowledges that the characteristics of those deemed to be in need of EoLC is changing, with a significant increase in non- malignant patients. This reflects the structure of the model, described in section 4, which groups patients into those with malignant tumours, those with long-term conditions and the frail elderly. This is not only increasing the number who are seen to be in need of EoLC but also their characteristics and therefore the nature of the services required. This is linked to idea 86, which recognises the ageing population. Idea 9 focuses on the time pressures faced by health professionals and the difficult this creates for providing end-of-life services, especially in initiating end-of-life conversations. Associated with this is the fact that many GPs see very few patients at end-of-life so have limited experience which, when combined with limited training, means that many are uncomfortable talking about end-of-life. This results in burnout for a significant number of GPs and also many who will not do home visits, which are an essential ingredient of EoLC. Idea 97 highlights the inappropriate expectations held by many carers who continue to ask for, and expect, curative treatment, resulting in further admissions to hospital, increased workload for hospital staff, and the resulting difficulty they have meeting the needs of a growing number of patients.

Figure 14: Provider Capability



5.4.2 Provider Capability: Designing Interventions

The logic of the map highlights some potential areas for intervention. Potential interventions to consider are:

1. Ensuring that all carers, in the early stages of EoLC provision, are provided with information that helps them develop appropriate expectations for what can be done for the patient.
2. Given the central role of GPs and the fact that not all GPs will be willing, or capable, of providing EoLC, explore the potential of establishing what are referred to as ‘GPs with a Special Interest’ (GPwSI). These are GPs with an interest in, the provision of EoLC. The PHN could support these GPs through i) publicity, to ensure appropriate services and individuals are aware of their existence; ii) training through, for example, programmes such as PEPA and potentially, iii) additional funding to support services such as home visits after-hours.

5.4.3 Provider Capability: Goals

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

1. The development of a register of GPs, and other health professionals in primary and community care, who are willing and able, to provide EoLC in their community.
2. Time spent by Palliative Care specialists in the provision of ‘events’ and other resources that help build capability amongst health professionals in primary and community care.
3. Time spend by health professionals in primary and secondary care supporting the capability of community-based care networks.

6. WORKFORCE[16]

The model discussed in section 4 was also used to undertake initial workforce analysis, specifically to explore the workforce implications of increased identification and recognition of those with EoLC needs.

6.1 Estimating Workforce Requirements

This is a complex and uncertain endeavour, as there are significant gaps in knowledge about the scope of existing service provision [as discussed in section 3]. As a consequence estimating the workforce that supports current service levels and the workforce that would be required to support any further improvements is very difficult to do. So, rather than trying to calculate total workforce requirements the model has focused on providing estimates of the *additional* workforce that would be required for any changes in the model of care. To do this we have tried to answer two questions. Firstly, *what* work would the workforce do, and secondly *who* would do it.

To answer the second question, rather than look at different occupational groups, we specified the functional requirements, splitting them into three categories. These are:

1. **Generic skills:** meaning care or support that does not require training at a qualified or specialist level. These skills can be held by many health professionals.
2. **Enhanced skills:** meaning tasks requiring competence that might be typical of an experienced member of staff, who has obtained skills that are transferable across a number of individuals at end-of-life.
3. **Specialist skills:** meaning tasks that require knowledge of direct relevance to the condition(s). These may relate to the primary condition, the secondary condition or palliative care.

To answer the first question we developed a template that explored the tasks required during a person's last year of life [the completed template is shown in appendix 2]. This template was developed from discussions with health professionals who had experience in working with patients at the end of life. These included palliative care specialists, palliative care nurses as well doctors, nurses and allied health professionals working in primary and community care.

The template provides a description of the tasks required, along with estimates of the time required to complete the tasks as well as the functional requirements, using the descriptions described above. This template allowed us to estimate the time required for every new person that was identified.

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[16] The approach we have used for the workforce modelling has been based on work undertaken in the UK. Details of this work can be found at http://www.thewholesystem.co.uk/population-health- needs/end-of-life-care/

Using these templates it is estimated that to identify, invite for assessment and assess each patient the time needed is approximately 235 minutes per patient. Of this time, 145 minutes was needed from staff with generic skills, while 90 minutes was required from staff with enhanced skills [see appendix 2: Entering the EoLC Pathway]. No specialist skills are needed at this stage. The specialist role becomes important once a patient had been identified as needing EoLC.

Despite the obvious individual variation that exists amongst patients, there was enough consensus about the tasks required and the time needed to compete those tasks for the first stage, identification and assessment, that we have included estimates of the additional workforce required for increases in the number of people identified and assessed [see section 6.2 below].

At this stage it is not possible to estimate additional workforce required throughout the last year of life however as there is still too much uncertainty about the time needed for the different tasks. This is an area where further research is required. As a consequence we would recommend that the PHN seeks support from NSWHealth, ACI and other PHN's to explore a joint research project to capture the data needed to complete the template discussed above and shown in appendix 2.

6.2 Improving Identification and Assessment

As discussed in sections 3 and 4, it is acknowledged that the numbers of people who are in need of EoLC are in excess of those receiving care. This is especially the case for non-malignant patients. While it is not known what percentage of patients are identified and assessed, it is accepted that it is much higher for cancer patients.

This is understandable given the long association between cancer services and EoLC. Based on input from Palliative and EoLC clinicians the model has a baseline assumption that the levels of identification and assessment across the different trajectories are:

Patients with malignant tumours	80%
Patients with long-term conditions	40%
Older frail patients	40%

To explore the workforce implications of improved identification and assessment a number of scenarios were tested. The first scenario looked at the implications of increasing the identification rate for people with long-term conditions from the baseline level of 40 percent to 80 percent. Figure 14 shows that the number required using the baseline assumptions is around 6 generic staff (FTE's). If the identification rate for people with long-term conditions was increased to 80 percent this would rise just under 8 FTEs.

Figure 15: Identification and Assessment – generic staff FTEs

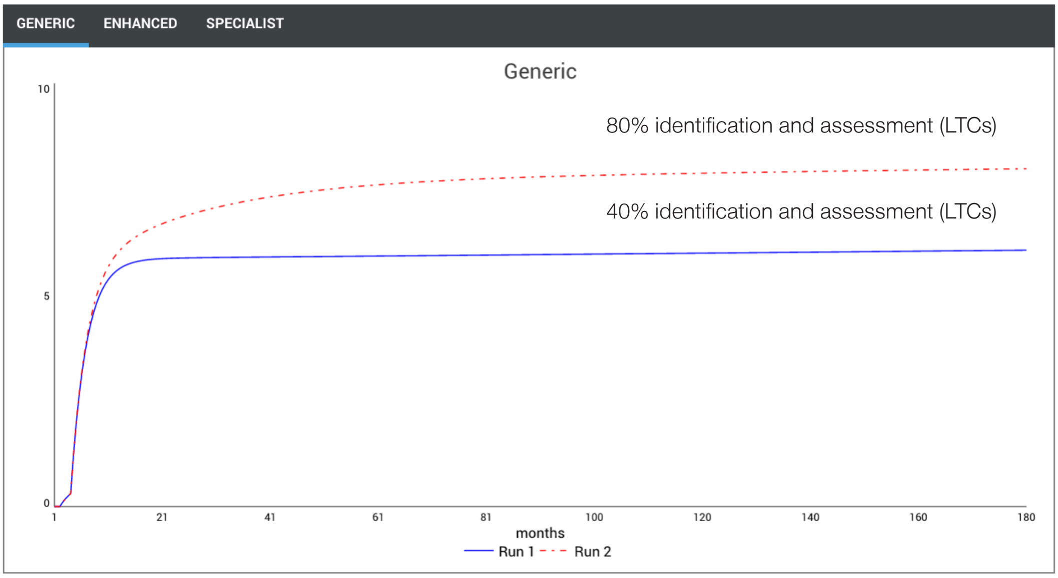
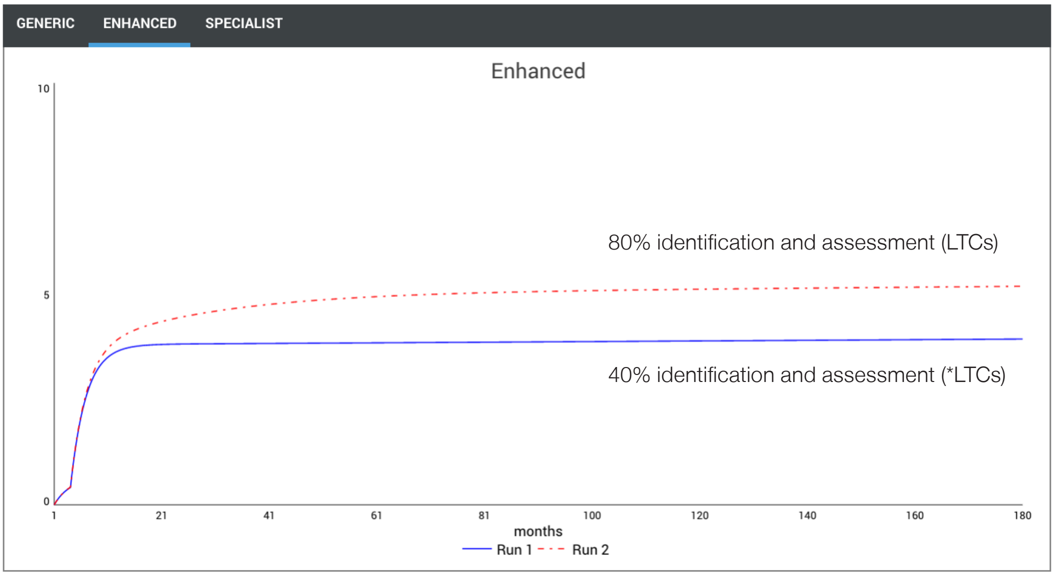


Figure 15 show the implications for enhanced staff, that is those who have experience and or training working with people at end of life. In this case increasing the number of people with long-term conditions from the baseline of 40% to 80 percent would require an increase in enhanced staff from just under 4 FTEs to a fraction over 5 FTEs.

Figure 16: Identification and Assessment – enhanced staff FTEs



Combining these two outputs, the model estimates that increasing the identification and assessment of patients with long-term conditions from 40 to 80 percent would require an additional 2.8 FTEs. NOTE: these additional FTEs are needed to carry out the tasks required to identify and assess patients. The additional staff needed to provide EoLC for this increase in identified patients is not included.

7. RECOMMENDATIONS

The following table summarises the recommendations made in this report.

Initiating End-of-Life Discussions

1. Provide training in EoLC for GPs and other primary and community care health professionals.
2. Provide training, education and/or support for carers.
3. Establish ‘flags’ and protocols to ensure that patients with EoLC needs are immediately recognised when they arrive in the emergency department (ED) and, wherever possible, are seen by a more experienced clinician.
4. Assist in ‘normalising’ death through initiatives such as ‘death cafes and ‘Dying to Know Days’.
5. Recognise that care networks are much bigger than health and begin by identifying current informal care networks that already exist.
6. Support GPs and other primary care providers, including those in RACFs to have end-of-life conversations, for example through ‘relative days’ at the RACF.
7. Establish a ‘Key Leaders Group’ to become the focal point and driver of many of the recommendations discussed in this report. This Group should also work with EoLC service providers in the region to improve data-sharing and the subsequent analysis of service need versus provision and identification of opportunities to close service gaps.

Use of Advance Care Plans

1. Establish a set of core principles that should guide the design and use of ACPs, including protocols for how it should be presented to patients and/or their carers.
2. Develop education material and workshops to explain the primary role of ACPs to support the initiation and development of appropriate and timely end-of-life conversations, and the mobilisation of the resources needed to support the patient.
3. Facilitate conversations amongst RACFs to support the adoption of points 1 and 2 above.
4. Undertake work to clarify the purpose of ACPs (to support conversations and mobilisation of resources) as well as key terminology used within them.
5. Explore ways of improving the accessibility of ACPs within the medical health record.
6. Review samples of current ACPs and use those to develop guidelines on their design and use.

Culturally Appropriate Services

1. Provide resources that support the recruitment and retention of Aboriginal and Torres Strait Islander staff and other staff that represent the cultural mix of the Nepean Blue Mountains region. Thought may also need to be given to the development and/or provision of training programmes to support the development of such people if they do not possess the skills needed for such positions.

2. Work closely with the Aboriginal health unit and the multicultural health services at the Local Health District (LHD) to explore cooperative approaches the to the recruitment and development of a more diverse workforce providing EoLC.

3. Work with the Aboriginal Liaison officer to promote, and design if required, in-house programmes to improve the cultural literacy of key PHN staff.

4 Establish a CALD resource co-ordinator, who would provide a navigation role, assisting patients and their families link with the people and services most appropriate for their needs.

Provider Capability

1. Ensure that all carers, in the early stages of EoLC provision, are provided with information that helps them develop appropriate expectations for what can be done for the patient.

2. Given the central role of GPs, and the fact that not all GPs will be willing, or capable, of providing EoLC, explore the potential for establishing what are referred to as ‘GPs with a Special Interest’ (GPwSI). These are GPs with an interest in the provision of EoLC. The PHN could support these GPs through publicity, to ensure appropriate services and individuals are aware of their existence; training through, for example, programmes such as PEPA and potentially, additional funding to support services such as home visits after-hours.

Service and Workforce Review and Development

1. PHN seeks support from NSW Health, ACI and other PHN’s to fund a joint research project to work with clinicians to capture the data needed to complete the template discussed in section 6 and shown in appendix 2.

2. Concurrent engagement with EoLC service providers to foster a collective understanding of the value of data sharing to improved service provision for the region and effective PHN commissioning processes.

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APPENDIX 1
– STAKEHOLDER CONSULTATION

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Cecile Dinh	General Practitioner	Springwood Family Practice
Michelle Shiel	Manager Low Acuity Care	NSW Ambulance
Melissa Jay	Clinical Nurse Specialist – Palliative Care	Anglicare
Kerrie Noonan	Director, co-Founder	The Groundswell project
Dr Alan Oloffs	Senior Staff Specialist, Head of Department, Supportive & Palliative Care	NBMLHD
Linda Ora	Clinical Nurse Consultant - Palliative Care | Primary Care and Community Health	NBMLHD
Kate Tye	Senior Manager – Populations in Focus	NBMPHN
Elisa Manley	Executive Manager, Operations, Planning and Integration	NBMPHN
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Sonia Cox	Aboriginal Liaison Officer	NBMLHD Community Health Primary Care & Community Health
Dr Cecile Dinh	General Practitioner	Springwood Family Practice
Debbie Horsfall	Professor, School of Social Sciences and Psychology	Western Sydney University
Donna Jory	Aboriginal Liaison Officer	NBMLHD Aboriginal Unit
Dr Faizal Kakkat	Senior Hospitalist/Geriatrician	NBMLHD
Dr Alan Oloffs	Senior Staff Specialist, Head of Department, Supportive & Palliative Care	NBMLHD
Linda Ora	Clinical Nurse Consultant – Palliative Care | Primary Care and Community Health	NBMLHD
Rebecca Palmer	Transitional Nurse Practitioner	NBMLHD
Eliza Pross	Aboriginal Consultant for NBMPHN	NBMPHN
Cate Salter	Aged Care Nurse, Practitioner	NBMLHD
Gordana Kostadinovska	Manager Multicultural Health	NBMLHD
Vicki Thom	Aboriginal Liaison Officer	St John of God Hospital
Mad Mob	Aboriginal Elders Group	Hawkesbury LGA
Anna Whitney	Facility Manager	Fitzgerald Memorial Aged Care Facility
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Gilbert Villavicencio	R/ Care Manager	Summitcare, St Marys
Wagdy Kaleeny	R/ Care Manager	Hardi Aged Care
Richard Norris	Care Manager	Opal Anita Village
Joy Egan	Director of Nursing	The Ritz Aged Care
Jill Comuzzo	Residential Manager	Bodington Catholic Healthcare
Lauren Stanley	Manager	Hawkesbury Living
Sharon Holt	Chief Executive Office	Lithgow Aged Care Services
Heather Ginard	Care Services Manager	Uniting Care Springwood Village
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APPENDIX 2 – WORKFORCE ANALYSIS

The following tables describe the tasks that are required during a patient's last year of life. The table describes the task, the functional workforce required, using the generic, enhanced and specialist functions described in section 6, and the time [in minutes] needed to undertake those tasks. These tables provide the basis for estimating workforce requirements.

NOTE: the times shown for the table describing the tasks involved in 'entering the EoLC pathway' have enough agreement amongst clinicians to be used in the model. That is not the case for the other tables and the data in them needs to be considered as tentative and indicative only. At this stage they are not robust enough to be used for workforce planning [see recommendations].

Entering the EoLC Pathway:

This is a one-off occurrence on the pathway and covers all diagnostic categories and levels of severity. Requirements for the functions is timed in minutes. Triggers include diagnosis, pain/symptom relief need, mobility support needed, some assistance with personal care needs, frequent admissions to hospital.

Code	Tasks	G	E	S
1	**Identify Patient**			
1.1	Screening (eg. using computerised SPICT, SPICT or surprise question)		15	
2	**Invite Patient for Assessment**			
2.1	Telephone invitation, letter, opportunistic, pop-up reminder in patient management software, part of routine health assessment	15		
3	**Conduct Assessment**			
3.1	Review patient records for medical history, medications, recent hospitalisations	20		
3.2	Review patient symptoms using a validated tool (eg. iPOS)	20		
3.3	Review patient care needs using a validated tool (eg. NAT-CC patient)	20		
3.4	Review caregiver needs using a validated tool (eg. NAT-CC carer)	20		
3.5	Assess Advance Care Planning needs and status (eg. using Advance Care Planning screening tool)		15	
3.6	Physical examination	10		
3.7	Organise investigations, follow up results, discuss results	20		
3.8	Formulation of the management plan (includes discussions with the primary GP, other doctors and health professionals)		30	
3.9	Discuss the plan with patient and caregivers		30	
3.10	Documentation into patient records	20		

Management of Symptoms and Care Needs: Severity Level 1

This is an ongoing occurrence on the pathway and covers complex patients who will require referral to specialist Palliative Care. Requirements for the functions is timed in minutes.

Code	Tasks	Frequency	G	E	S
1	**Review and Initial Management**				
1.1	Specialist (doctor) review and management	monthly	5		60
1.2	Palliative care nursing review and mgt – initial	monthly	5		60
1.3	Palliative care allied health review and mgt – initial	monthly			60
1.4	Referral to other non-palliative care specialists	one-off	5		
1.5	Assessment by other non-palliative care specialists	monthly	60		
1.6	Referral to Community based allied health	one-off	10		
1.7	Community based allied health review and mgt – initial	monthly	60		
1.8	Prescription of symptom relief medications (eg. opioids and analgesics, anti-nauseants)	fortnightly	15		10
1.9	Referral to Aged Care Assessment Team (ACAT) (if required)	one-off	30		
1.10	Aged Care Assessment Team (ACAT) review (if required)	Bi-monthly	60		

Management of Symptoms and Care Needs: Severity Level 2

This is an ongoing occurrence on the pathway and covers complex patients with advanced care needs requiring referral to palliative care nursing, but with GP oversight. Requirements for the functions is timed in minutes.

Code	Tasks	Frequency	G	E	S
1	**Review and Initial Management**				
1.1	Home medication review by GP (depending on need)	monthly		30	
1.2	Home medication review by Pharmacist (depending on need)	2-monthly	30		
1.3	Assist patient with Advance Care Planning	3-monthly		45	
1.4	Prescription of symptom relief medications (eg. opioids and analgesics, anti-nauseants) 15 mins to write script and discuss with patient and 15 mins for Pal Care nurse to make recommendation	fortnightly	15		15
1.5	Palliative care nurse review and mgt – initial	monthly	5		60
1.6	Referral to other non-palliative care specialists	one-off	5		
1.7	Review by other non-palliative care specialists	one-off	45		
1.8	Referral to Community based allied health	one-off	10		
1.9	Community based allied health review and mgt – initial	monthly	60		
1.10	Referral to Aged Care Assessment Team (ACAT) (if required)	one-off	30		
1.11	Aged Care Assessment Team (ACAT) review (if required)	one-off	60		

Management of Symptoms and Care Needs: Severity Level 3

This is an ongoing occurrence on the pathway and covers patients with basic care needs that could be managed by the primary care team. Requirements for the functions is timed in minutes.

Code	Tasks	Frequency	G	E	S
1	**Review and Initial Management**				
1.1	Home medication review by GP (depending on need)	monthly		30	
1.2	Home medication review by Pharmacist (depending on need)	2-monthly	60		
1.3	Assist patient with Advance Care Planning	3-monthly		45	
1.4	Prescription of symptom relief medications (eg. opioids and analgesics, anti-nauseants)	monthly	15		
1.6	Referral to other non-palliative care specialists	one-off	5		
1.7	Review by other non-palliative care specialists	monthly	45		
1.8	Referral to Community based allied health	one-off	10		
1.9	Community based allied health review and mgt – initial	monthly	60		
1.10	Referral to Aged Care Assessment Team (ACAT) (if required)	one-off	30		
1.11	Aged Care Assessment Team (ACAT) review (if required)	one-off	60		

Management of Symptoms and Care Needs: Last Days (dying at home)

Requirements for the functions is timed in minutes.

Code	Tasks	Frequency	G	E	S
1	**Managing Symptoms and Care Needs**				
1.1	Home visit for assessment (including history, examination, investigations as required)	one-off		60	
1.2	Phone support	weekly		20	
1.3	Prescriptions and medication reviews	weekly	20		
1.4	Specialist (doctor) review and management (if required)	Monthly for X% of patients	5		60
1.5	Refer to Palliative care nursing support	one-off	5		
1.6	Palliative care nursing support	Fortnightly			60
1.7	Community based allied health review and mgt – initial	monthly	10		
60					
1.7	Support from Home Care Package providers (self-care, cleaning, transport, meals, medication and nursing support) – at least once a day		Intensive		
1.8	Last 48 hours – intensive palliative care nursing support: • Community care workers • Palliative care nurses			240	120

Management of Symptoms and Care Needs: Last Days (dying in RACF/Hospital/Hospice)

Requirements for the functions is timed in minutes.

Code	Tasks	G	E	S
1	**Managing Symptoms and Care Needs**			
1.1	Conduct assessment (including history, examination, investigations as required)		60	
1.2	Prescriptions and medication reviews (at least weekly)	As required		
1.3	Specialist (doctor) review and management (if required)	5		60
1.4	Refer to Palliative care nursing support	5		
1.5	Palliative care nursing support			60
1.6	Last 48 hours – intensive palliative care nursing support		Intensive	Intensive

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