SYNERGIA

IMPROVING SERVICES FOR PEOPLE WITH DEMENTIA IN THE NEPEAN BLUE MOUNTAINS REGION

Report for Wentworth Healthcare Ltd., Provider of the Nepean Blue Mountains Primary Health Network

Final Report

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An Australian Government Initiative

Wentworth Healthcare
Blue Mountains | Hawkesbury | Lithgow | Penrith

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Executive Summary

This report describes the project undertaken for Nepean Blue Mountains Primary Health Network (NBMPHN) to explore and understand dementia care and the key issues facing the provision of dementia services in the Nepean Blue Mountains region. This work is driven by a concern about the current gap between current need and current services and the significant growth projections for dementia in the region.

The aim of this work has been to better understand both the size and nature of the service gaps in dementia care, why those gaps exist, what needs to be done to close those gaps and to provide a set of recommendations to guide strategies to improve current services and/or provide new services in the region.

One piece of work involved the development of a simulation model to provide improved estimates of need, utilising national and regional data as well as the research evidence, as it pertained to dementia prevalence and incidence in Australia. A second piece of work involved a review of current services to better understand their nature and scope, and to highlight the gap between need and current service provision. A third piece of work involved interviewing health professionals and carers to identify the key issues that would need to be considered in future planning to close these gaps. These service gaps and key issues were explored using system maps to describe the issues and identify leverage points that could help to close the gaps and ensure that any changes to current service provision reflected local need.

Understanding the issues and challenges for dementia care 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 design and commissioning of dementia services in the region.

The purpose of this report is to provide guidance for the PHN in future commissioning of dementia services in the region. The issues that our recommendations focus on fall under five key headings:

1. Early diagnosis
2. Service gaps
3. Poor Morbidity and Mortality Rates
4. General Practitioners
5. Equity

1. Introduction and Context

Synergia was commissioned in April 2018 by the Nepean Blue Mountains Primary Health Network (NBMPHN) to assist the PHN to increase their understanding of dementia services in their region and the need for those services. A simulation model was proposed to provide estimates of future need to support future planning and commissioning of dementia services for the region.

The specific aim of the project as described in the Project Brief was to :

"To improve the manner in which Primary Care undertakes early diagnosis, referral, intervention and care for people with dementia in the Nepean Blue Mountains Region."

During the detailed scoping of the project it was also agreed that the involvement of the specialists in the Local Health District (LHD) was key, and they have been closely involved in the development of this report.

1.1 The Approach

The project has three key components:

- the development of a simulation model,
- the mapping of current services and
- identifying key service issues.

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

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 29 people from the region as well as analysing relevant documentation and databases. Three 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.

The development of the simulation model involved the analysis of national and regional data as well as research on the prevalence and incidence of dementia. This data was incorporated into the model so that estimates of need could be calculated.

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 dementia services in Nepean Blue Mountains to support

the PHN with future dementia service planning, commissioning and ongoing improvement of current dementia 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%

[1] Australian Bureau of Statistics, 2016 Census.

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

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 (e.g. Lithgow) and regions with an increasing ageing population (e.g. Penrith).

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 for local dementia services. While Penrith has the largest numbers, the high percentage of people 65+ in Lithgow and the Blue Mountains poses particular challenges for dementia care in the region.

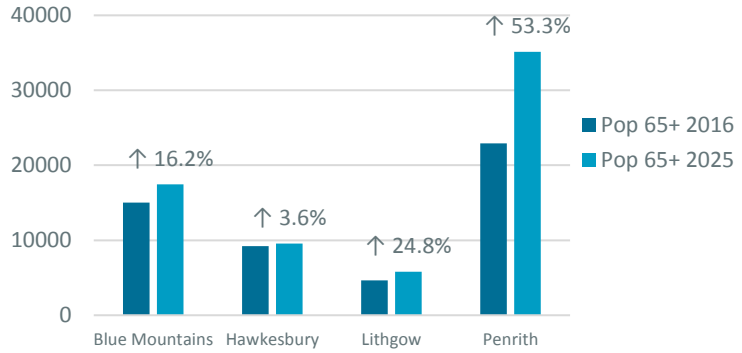


Figure 1: Expected Growth Population 65+

The current age profile of the region is very similar to the current NSW age profile. However, while the 65+ population is lower than the NSW average (figure 2) it is projected to grow at a slightly faster rate (figure 3).

[3] Australian Bureau of Statistics, 2016 Census.

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

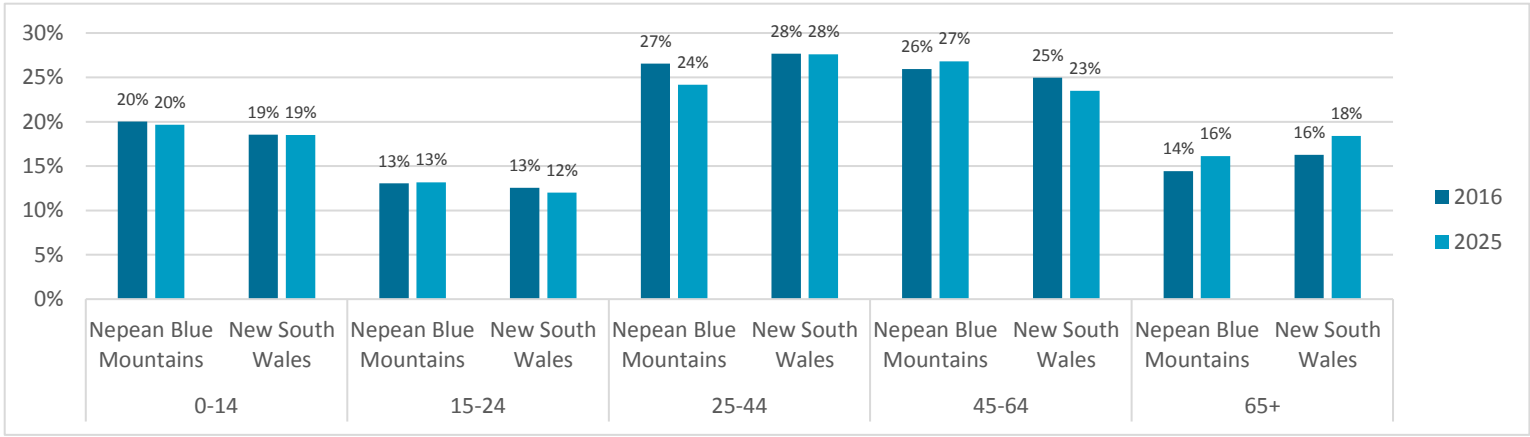


Figure 2: Percentage of the population by age from 2016 to 2025 for Nepean Blue Mountains and NSW

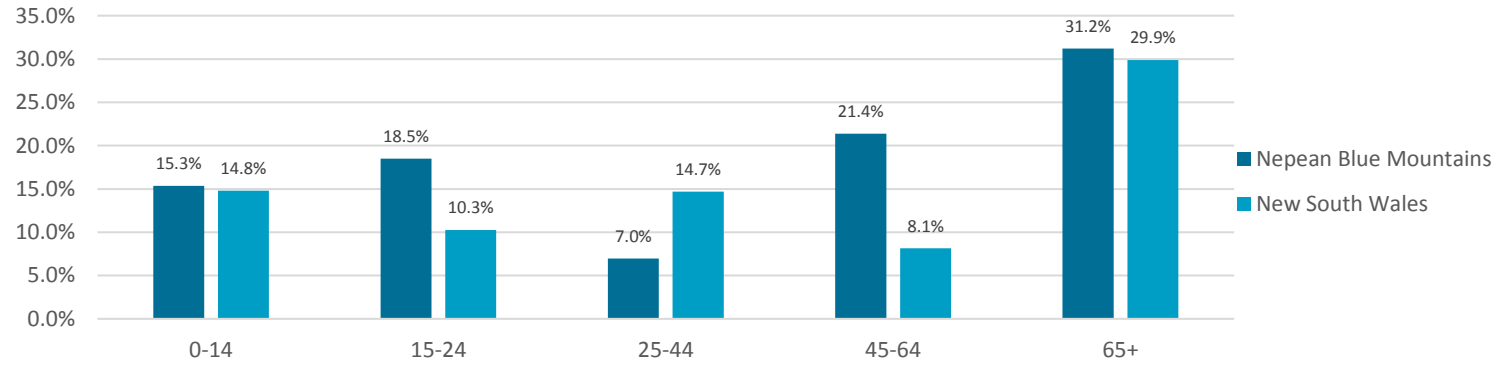


Figure 3: Expected population growth by age from 2016 to 2025 for Nepean Blue Mountains and NSW

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 pop
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. This has significant implications for the future of dementia services, which involve a set of complex interactions between the patient, their carer and health providers.

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.

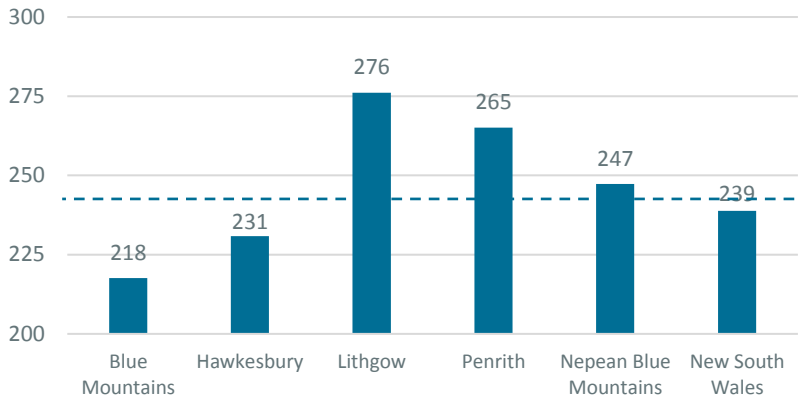


Figure 4: Avoidable Deaths persons under 75 (ASR per 100,000) 2010-2014

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

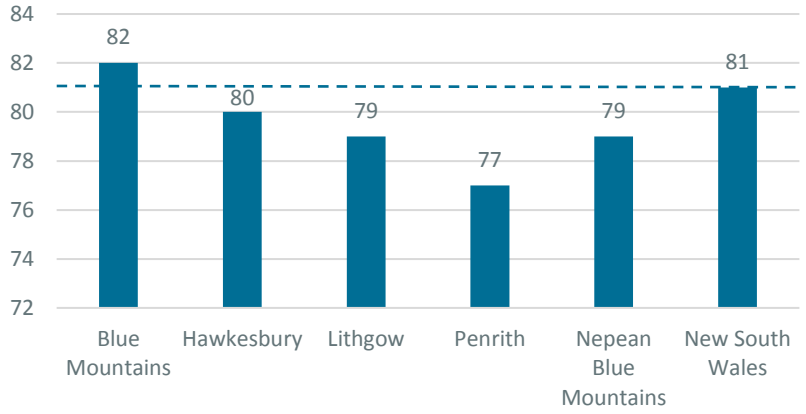


Figure 5: Median Age of Death (Years) 2010-2014

3. LOCAL SERVICE PROVISION

3.1 Service Mapping

A key task for the project was to map current services for dementia care in the region. Two key points emerged from this work. Firstly, it was clear that the further one was from Nepean Hospital, the more difficult it was to access services. Secondly, providing an easily accessible list of services was seen to be an important output that this project could deliver.

The data for this mapping was obtained from documentary sources[6] and interviews with health providers. The information was then uploaded to an interactive visual map that provided locality and service information for three groups of services:

- Residential Aged Care Facilities (RACFs)
- Clinicians and other health professionals providing dementia services
- Community and LHD services

The on-line interactive map is available at:

https://dementia-services.synergia.nz/#!/signin

To access these maps requires an email and password. To simplify access, a generic email and password has been created. These are:

email: nbmphn.dementia@synergia.com.au

password: NBMPHNDementia*8

The map will be updated as further information is obtained.

The following pages show high-level screen shots of the location of RACFs, Clinicians and other health professional and community and LGHD services. The interactive map allows you to filter along a number of dimensions and provides more detailed information by clicking on the relevant item on the map. It should be noted that each 'dot' on the map may, when you zoom in using the on-line version, show more than one service and/or health professional. The number of 'dots' does not therefore equate to the number services and/or health professionals providing dementia services.

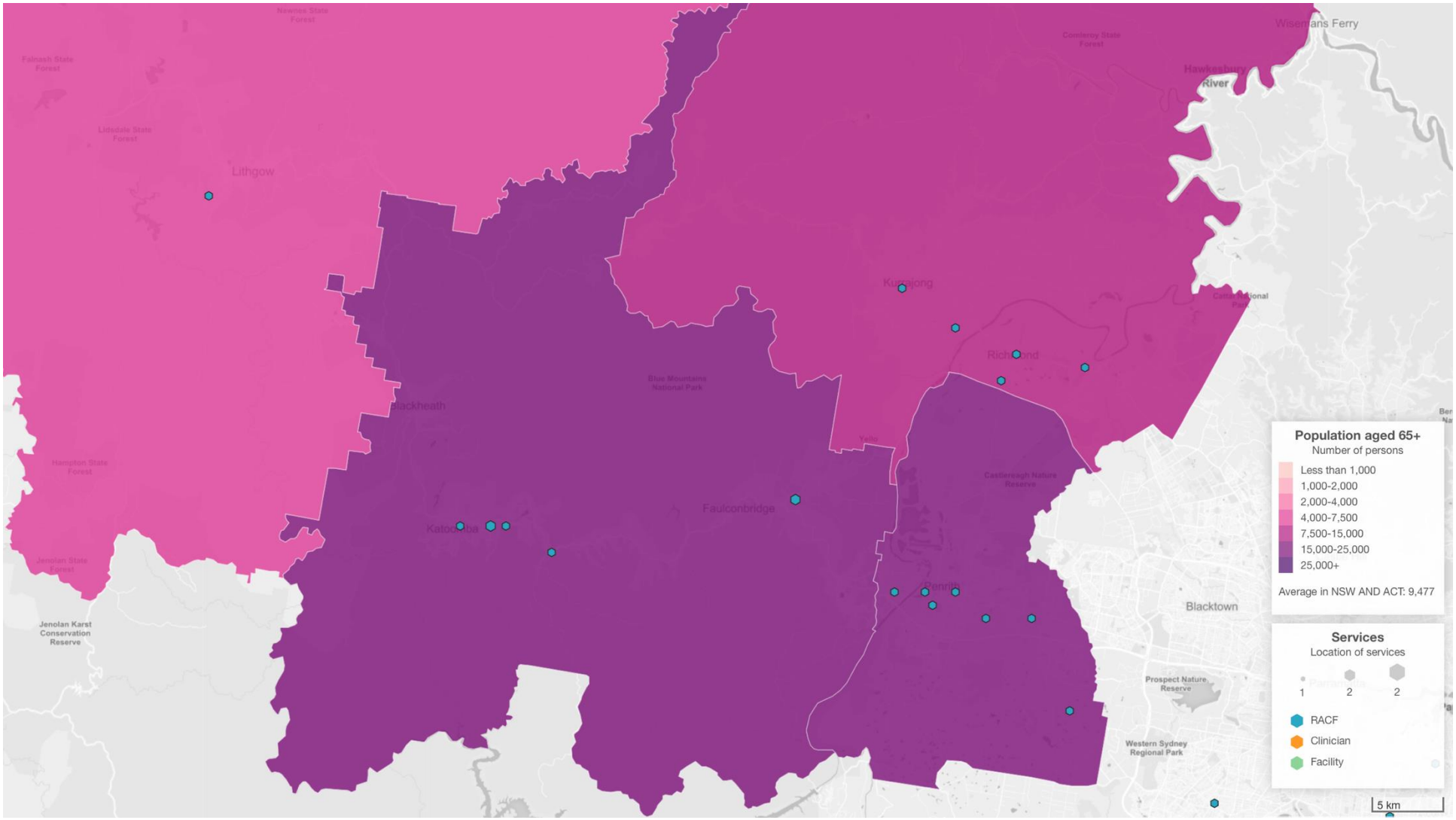
[6] The following sites provided information that was incorporated into the database:

- Aged Care Guide https://www.agedcareguide.com.au/
- Nepean Blue Mountains Local Health District https://www.nbmlhd.health.nsw.gov.au/
- St John of God https://www.sjog.org.au/our-locations/hawkesbury-district-health-service
- Dementia Behaviour Management Advisory Service (DBMAS) https://www.dementia.com.au/
- Health and Leisure to You https://www.healthandleisuretoyou.com.au/about-us

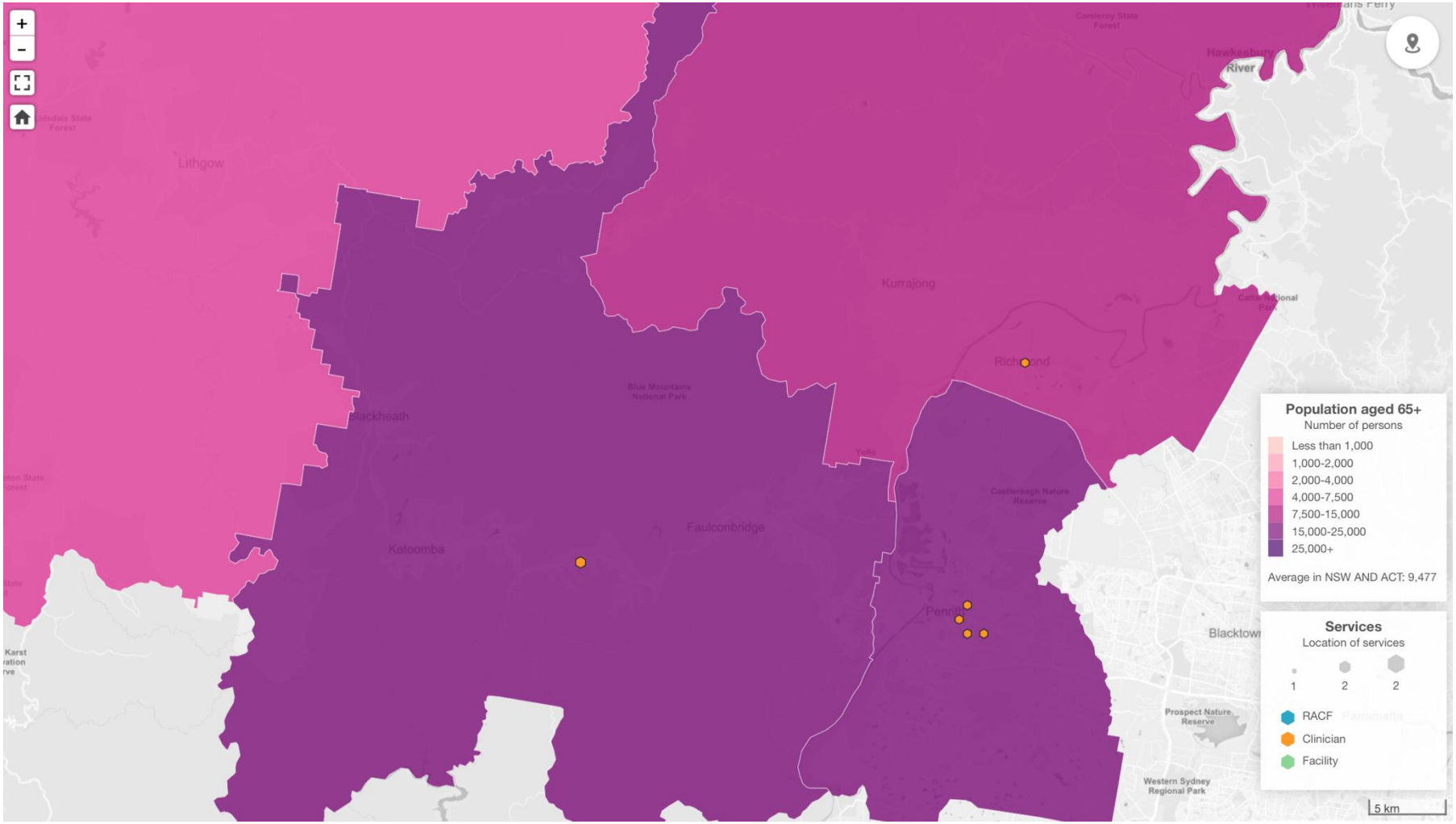
These high-level snapshots however do provide a good illustration of the concentration of services at Penrith and along the main Western arterial road. The further one is away from these two areas the harder it is to access services.

As noted above we are well aware that these maps do not include all services. However, the maps have been designed so that the modification of current service information and/or the addition of new services is an easy task to accomplish. Behind the on-line maps is a database that can be easily modified, the results of which are immediately apparent on the on-line maps. These maps should be viewed as a resource that will gain more value as more services are added and as the service descriptions are refined.

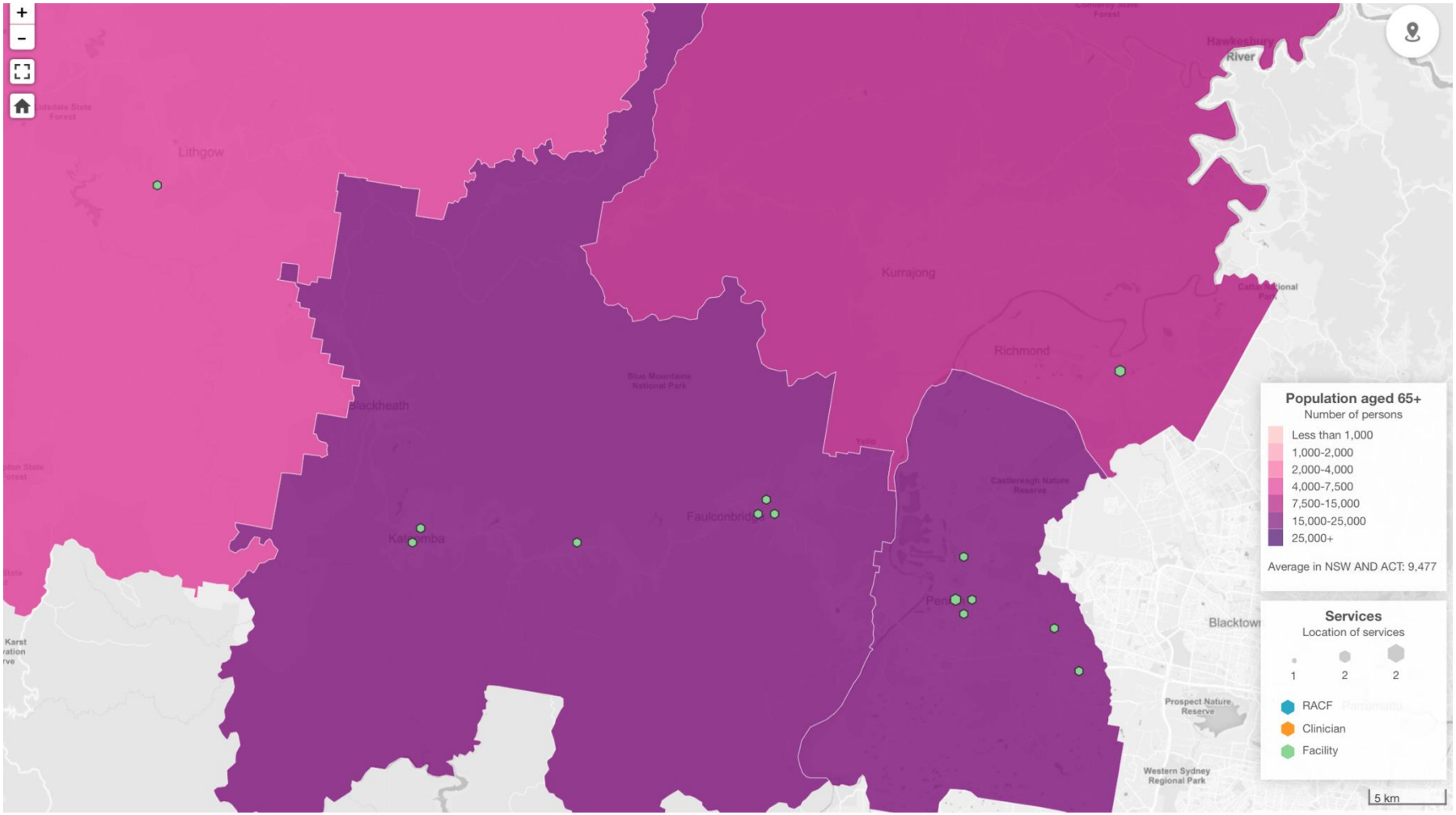
3.1.1 RACFs


Lithgow
Blackheath
Katoomba
Faulconbridge
Richmond
Blacktown
Wisemans Ferry
Blue Mountains National Park
Jenolan Karst Conservation Reserve
Prospect Nature Reserve
Western Sydney Regional Park
Population aged 65+
Number of persons
Less than 1,000
1,000-2,000
2,000-4,000
4,000-7,500
7,500-15,000
15,000-25,000
25,000+
Average in NSW AND ACT: 9,477
Services
Location of services
1
2
2
RACF
Clinician
Facility
5 km

3.1.2 Clinicians and other health professionals providing dementia services



3.1.3 Community and LHD services



3.2 Service Implications

As noted above, and as is clear from the maps shown, dementia services are concentrated in Penrith. As a consequence access to the services located within Nepean hospital are difficult to access for those not close to Penrith. While telemedicine initiatives undertaken by the Aged Care team in Nepean hospital are helpful and appreciated by providers and carers alike, equitable access to specialist services across the region is still a challenge. The lack of specialist geriatric or dementia staff at the Katoomba Hospital is indicative of this resource concentration.

Accessing services, especially in the early stages can therefore be very difficult for people. This is especially the case when trying to get a diagnosis. The ability of providers in primary care to provide a diagnosis is highly variable with many patients and their carers seeking out many General Practitioners (GPs) to get an answer to what, prior to the diagnosis, is a disturbing situation that they do not understand. Getting that diagnosis, and therefore access to appropriate services is, for many a long drawn-out, difficult, stressful and upsetting process.

As a consequence, people seek services outside of the region if they are able. For one Lithgow resident we interviewed, all the significant services they are accessing for himself and his partner are based in Sydney.

What this mapping exercise has done is shine a light on the concentration of services and highlight the negative consequences for patients and their carers on the difficulty, especially trying to obtain a diagnoses, of accessing services when they are largely concentrated around the Nepean hospital.

What this mapping does not comment on is the variable quality of services, especially in primary care. This will be discussed in section five.

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 dementia 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 simulation 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 estimating the number of people 65 plus with mild moderate and severe dementia.

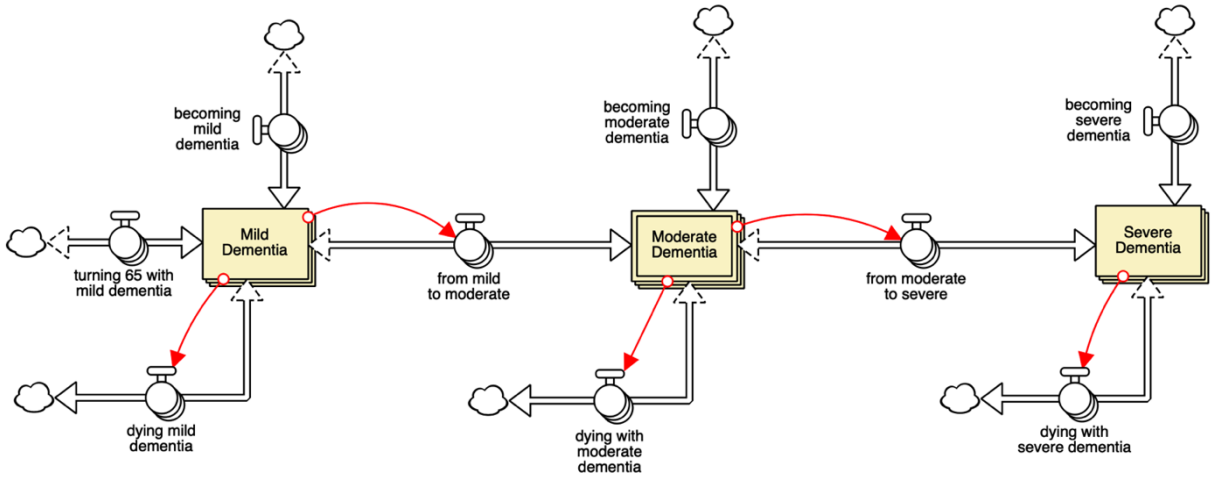


Figure 6: High-level Overview of Model

Data provided by the Australian Bureau of Statistics was used to estimate the population growth in the region[7] and the mortality rates, by age, within each of the four local government areas (LGA's)[8]. This provided the baseline data for the estimates used in the model. Estimates of dementia prevalence were obtained from Access Economics[9,10], and the Australian Institute of Health and Welfare (AIHW)[11]

Estimates of the split between mild, moderate and severe dementia was based on a number of international reports[12,13].

This analysis provided us with estimates of the number of people 65 plus living with mild, moderate and severe dementia.

The model runs for 30 years from 2016 to 2045.

To explore different scenarios and to test different assumptions, the model allows, through a simple interface (figure 7) the easy modification of incidence rates, progression rates from mild to moderate and progression rates from moderate to severe.

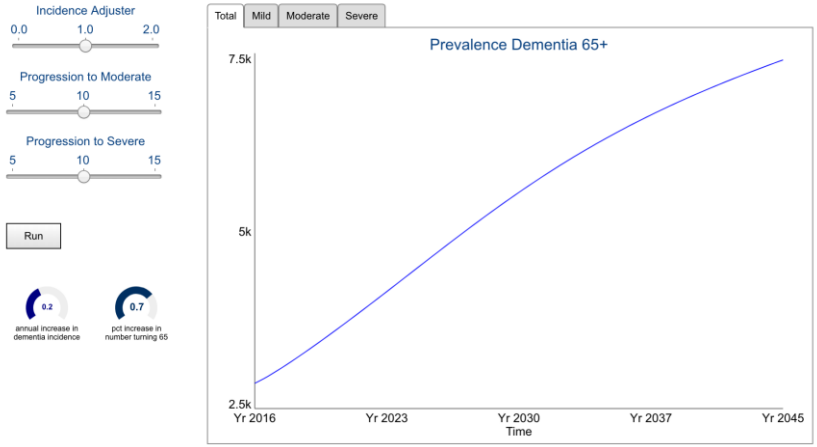


Figure 7: Model Interface to modify assumptions

[7] Australian Bureau of Statistics: Regional Population Growth, Australia. Released 30 March 2016.
[8] AIHW (Australian Institute of Health and Welfare) 2017. MORT (Mortality Over Regions and Time) books: Local Government Area (LGA), 2010–2014. Canberra: AIHW.
[9] Access Economics. 2009. Keeping dementia front of mind: incidence and prevalence 2009-02050.
[10] Access Economics. 2010. Caring Places: planning for aged and dementia care.
[11] Australian Institute of Health and Welfare 2012. Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW.
[12] Ansah, J. P., et al (2017). Projecting the Number of Elderly with Cognitive Impairment in China Using a Multi-State Dynamic Population Model. System Dynamics Review, 33(2)
[13] Rees, D. 2011. Care for People with Dementia. Report for Health Workforce New Zealand.

4.2 Population Baselines

The base line population projection for people 65 plus is shown below in Figure 8.

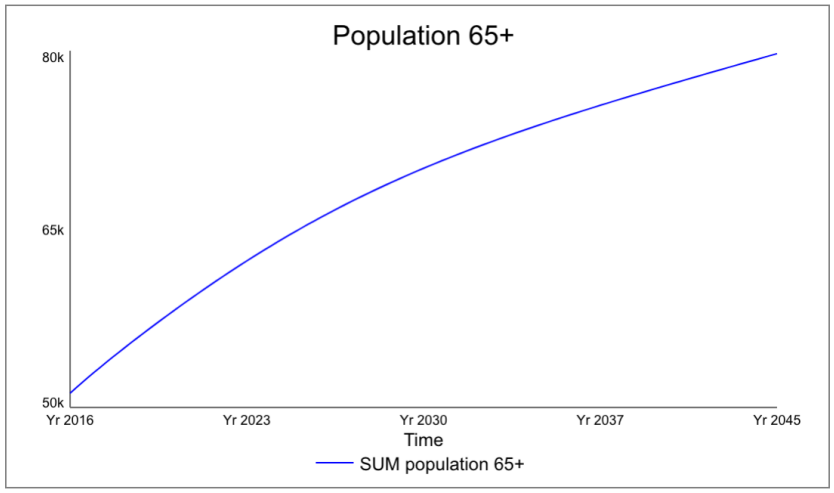


Figure 8: NBM Population 65+ Projection

The graph shows that the population 65 plus in Nepean Blue Mountains region was just over 50,000 in 2016 and estimated to grow to just under 80,000 by 2045.

4.3 People With Dementia

Figure 9 shows the estimated number of people living with dementia in the Nepean Blue Mountains region, rising from around 3,000 in 2016 to over 7,000 by 2045.

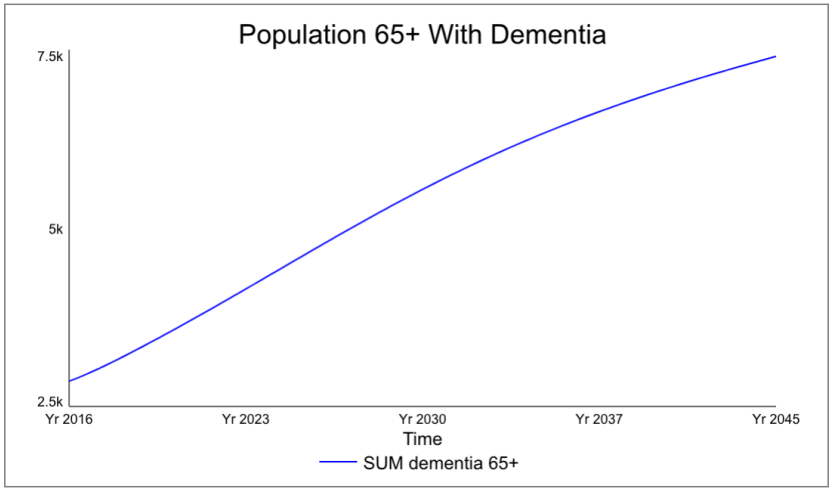


Figure 9: Deaths per Year

4.4 Estimates of Dementia Severity

Providing estimates of severity is less precise than estimates of overall prevalence. Despite those limitation however it is import to provide some figures as they affect the level and type of services required and an indication of the numbers seeking diagnosis every year.

The following three graphs show the estimated prevalence's of people with mild, moderate and severe dementia.

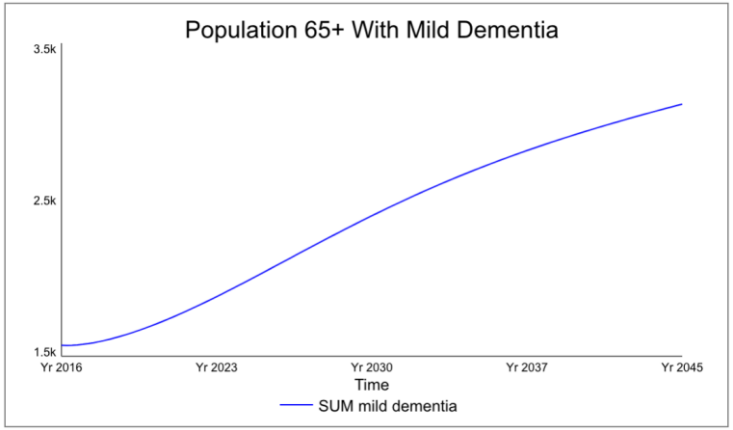


Figure 10: Estimated Prevalence of People with Mild Dementia

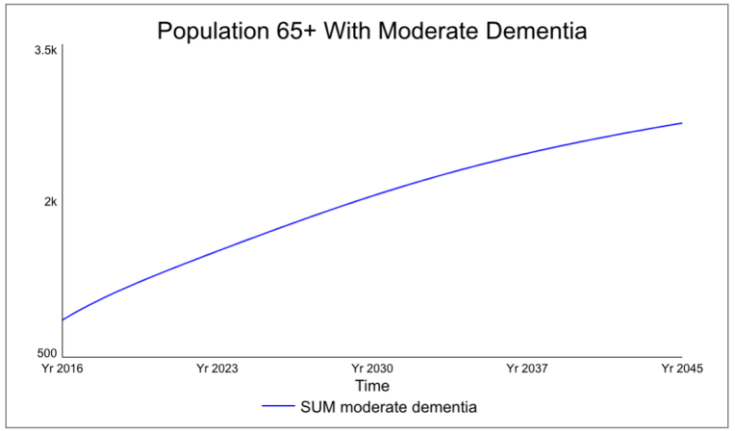


Figure 11: Estimated Prevalence of People with Moderate Dementia

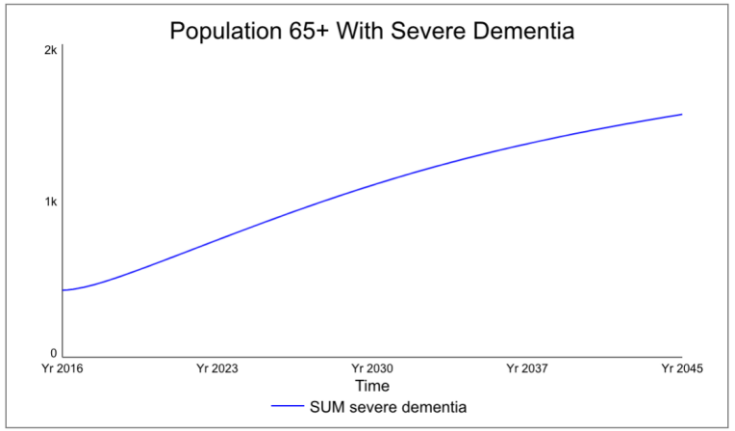


Figure 12: Estimated Prevalence of People with Severe Dementia

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

Broken down by severity our estimates indicate that those with mild dementia will drop from 55% to 42%, while those with moderate will rise from 30% to 37% and those with severe dementia will rise from 15% to 20%. While these figure need to be treated with caution they pose the challenge that not only are the prevalence numbers increasing but also, if current trends continue, the balance of need is going to move to the more severe end of the dementia continuum.

The issues that will need to be addressed given this rise in prevalence is discussed in the next section

"By 2056 without a medical breakthrough, we'll have around 1.1 million [people living with dementia] and there won't be anybody in Australia who won't be impacted in some way,"

Maree McCabe Chief Executive, Alzheinmer's Australia

https://www.abc.net.au/news/2018-02-28/new-figures-show-250-australians-developing-dementia-every-day/9490840

5. KEY ISSUES IN DEMENTIA CARE

5.1 Introduction

Our approach to understanding the issues facing dementia care in the Nepean Blue Mountains region was built on wide consultation, during which we interviewed a wide range of providers and carers throughout the region. This included people from community and primary health services, hospital services, not for profit providers as well as people working in RCFs. In total 29 people were interviewed. The purpose of these interviews was to understand the interviewees perspectives on:

- key issues being faced by dementia care 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 12) the idea '165 eventually referred to specialist'[15] influences '112 comprehensive early diagnosis. Simply, this is saying that being able to refer to a specialist is a contributing factor to a comprehensive early diagnosis. In contrast the arrow between '50 many factors can masquerade as dementia has a '-' sign attached. This means that the fact that it can be difficult to diagnose dementia, because many factors can give the impression that dementia is the underlying condition makes it more difficult to ensure a comprehensive early diagnosis. This map is discussed in more detail in the next section.

In these maps 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 maps, and the issues that emerged from them, were discussed during workshops held on 08 August and 18 October 2018. These discussions focused on the opportunities (what potential positive consequences could arise from successfully addressing the

[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 attached by the computer when the idea is entered. They are used by the computer to track ideas in the database. They do not indicate any value or priority given to any specific idea.

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

5.2 Early Diagnosis

Figure 13 below describes the set of interacting factors that surround the key issues relating to a comprehensive and early diagnosis.

5.2.1 Early Diagnosis: Mapping the Issue

Figure 1 is a cognitive map that illustrates the connections between ideas that relate to early diagnosis.

At the bottom of the map there are a number of drivers affecting early diagnosis (112)[16]. One relates to specialist referrals (165), another highlights the need to improve links between geriatricians and GPs (114). A third concept (50) refers to the complexity of diagnosis, due to the fact that many factors can masquerade as dementia when the underlying condition is quite different. The consequences of a comprehensive early diagnosis are significant. As the map outlines these include:

- (3) better targeting of medications
- ability to (124) establish what is reversible or not
- tap into (43) additional funding support for dementia patients

As the map also points out, the lack of a comprehensive early diagnosis can contribute to:

- (23) poor morbidity and mortality rates amongst dementia patients
- (35) poor communication of diagnosis, you've got dementia'
- A wrong diagnosis, (46) sometimes the dementia diagnosis is wrong – they don't have dementia

5.2.2 Early Diagnosis: Designing Interventions

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

- Improving access to specialist services, including geriatricians.
- Improving the links between geriatricians and GPs.
- Training, education and/or support for GPs to improve their ability to diagnose and communicate the results of that diagnosis to patients and their carers

[16] These number refer to the numbers associated with each concept. 112 is the concept in the following map '112 comprehensive early diagnosis'

5.2.3 Early Diagnosis: Goals

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

- The development of an integrated approach to 'early diagnosis that recognizes the important role played by GPs and the primary care team and the need for specialist support. Both are necessary for a comprehensive and early diagnosis to be more widely available.

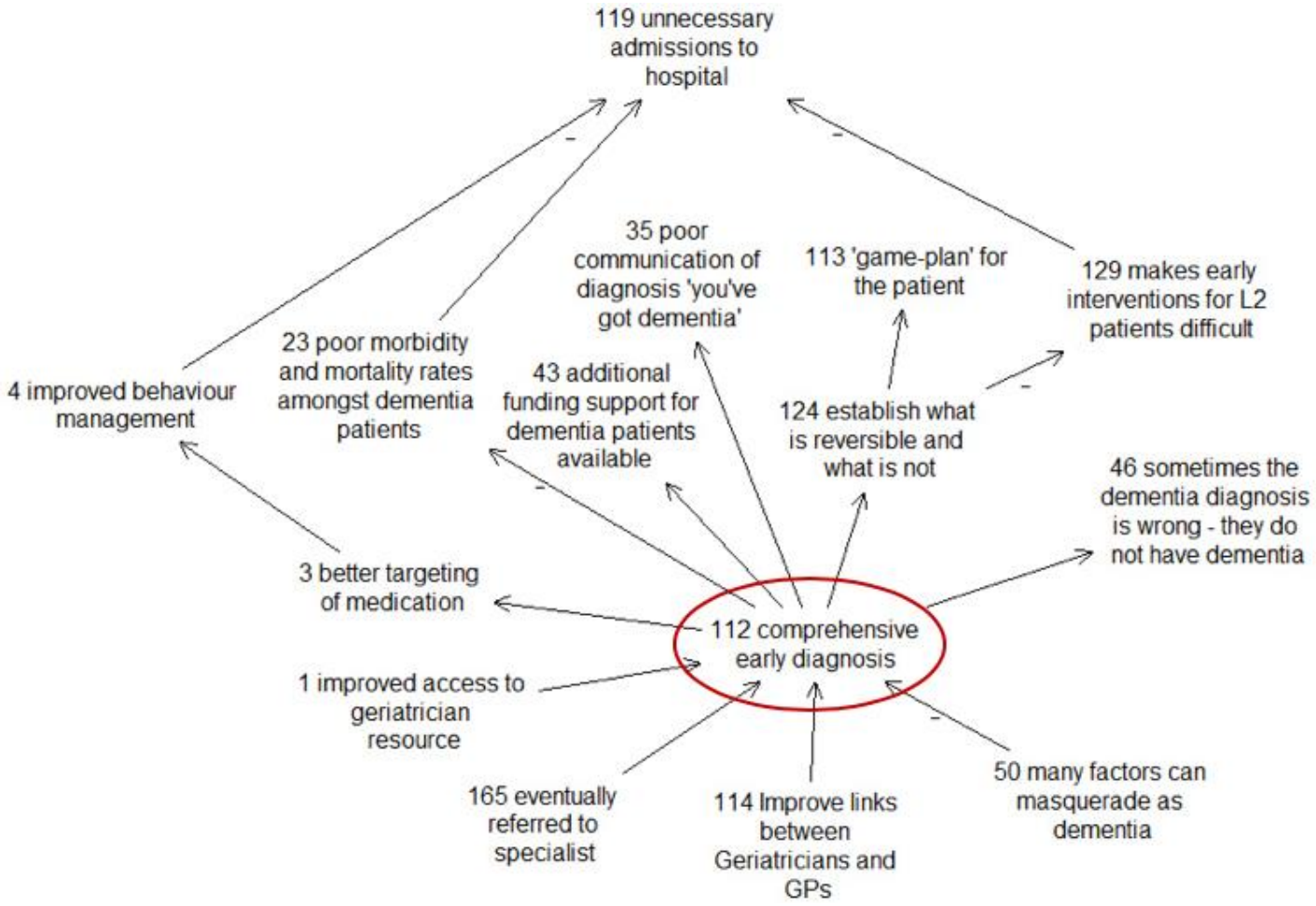


Figure 13: Comprehensive Early Diagnosis

5.3 Service Gaps

Figure 14 is a cognitive map that illustrates the connections between ideas that relate to the use of Advance Care Plans (ACPs).

5.3.1 Service Gaps: Mapping The Issues

At the bottom of the map there are a number of comments that reflect significant service gaps. A number of these (5, 27, 88 and 30) describe a specific service that is lacking. However, two of them (21 and 19) reflect knowledge and gaps and behaviours amongst GPs. These gaps have consequences not just for patients and their carers but also for the health system. These gaps contribute to poor patient outcomes (6 and 23), inappropriate referrals to ED (22 and 93).

5.3.2 Service Gaps: Designing Interventions

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

- A detailed review of current services and an exploration of whether or not there is a case for a geriatrician service at Katoomba, a unit to manage severe dementia, a step-down service
- A survey of the support needs of patients and carers to explore how those can be met with current and reconfigured services.
- Improved referral protocols from GPs to specialist service. This has close links to the opportunities discussed above in section 5.2.2.

5.3.3 Service Gaps: Goals

The map also highlights some potentials goals. These include:

- Reduction in unplanned admission of dementia patients to ED
- Improved access to basic health needs for dementia patients. For example, access to dental care for those in more outlying areas.
- Measurable improvements in the morbidity and mortality rates amongst dementia patients. While it was not a part of this project it would be worthwhile capturing data to establish how well dementia patients fare on these measures compared to other regions in Australia.

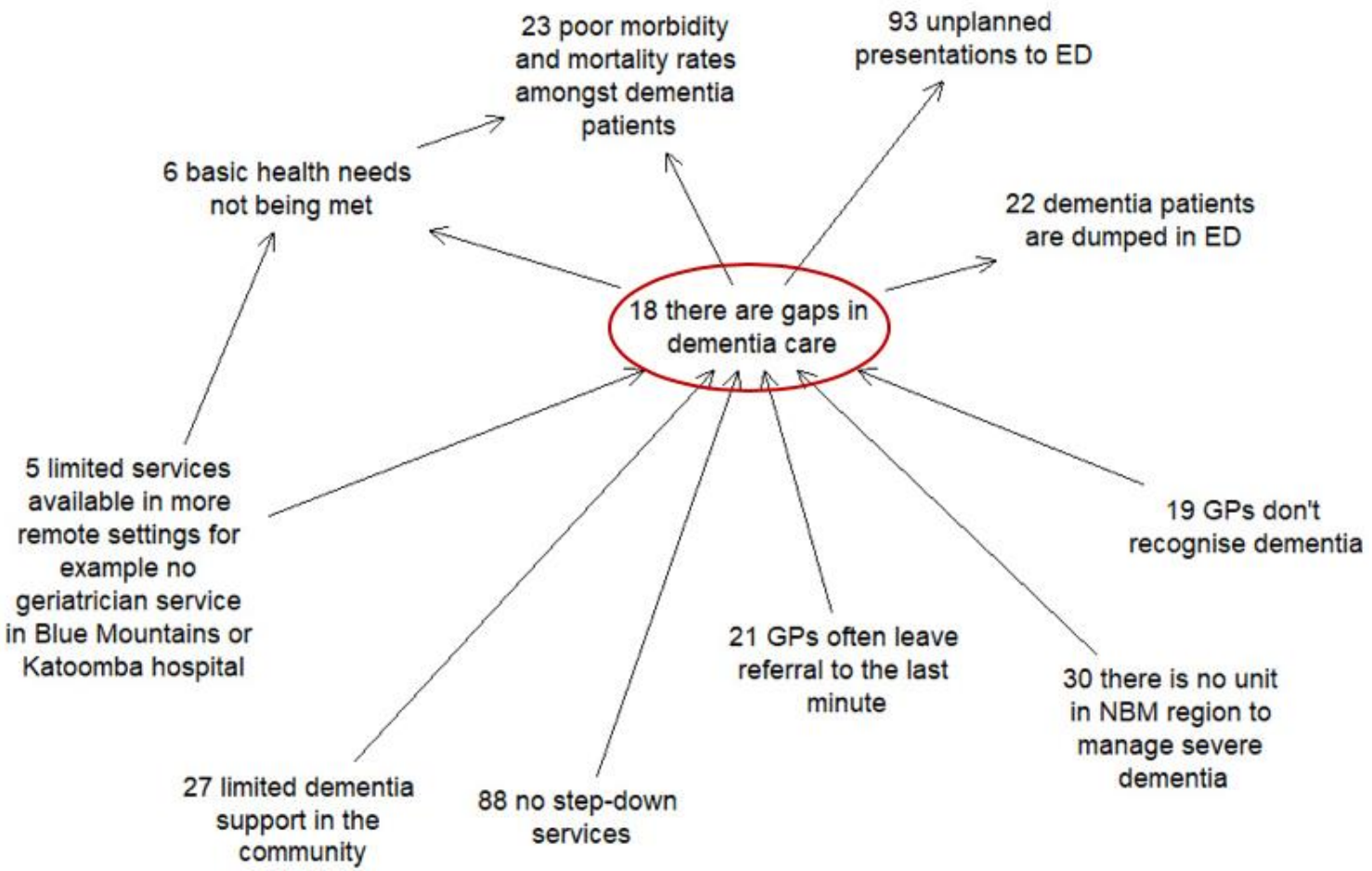


Figure 14: Service Gaps

5.4 Poor Morbidity and Mortality Rates

Figure 15 is cognitive map that illustrates the factors that drive poor morbidity and mortality rates and the consequences that result

5.4.1 Poor Morbidity and Mortality Rates: Mapping The Issues

The concept '23 poor morbidity and mortality rates' emerged as a central concept in a number of the issues. This map highlights a key pattern, raised by many people. In this pattern the poor morbidity and mortality rates and to '119 unnecessary admissions to hospital. Because these admissions are, for some patients, unnecessary they lead to the patients being discharged with the wrong diagnosis (121). This is also because the shortage of hospital beds (127) is putting pressure on discharges. A consequence of this is that patients go back to unsuitable living arrangements (125), resulting in them not getting the support they need (118), further contributing to poor health outcomes (23) and unnecessary ED admissions (119).

Key drivers of this are the issues raised above, namely the lack of comprehensive early diagnosis, with many diagnoses being late (115) and service gaps (5 and 18). This again highlights the interconnectedness of these issues and the need to ensure that specific service interventions are grounded in good system design that ensure the services can perform as intended.

5.4.2 Poor Morbidity and Mortality Rates: Designing Interventions

The map highlights some potential areas for intervention. Some potential interventions match those already noted above. Potential new interventions that this issue highlights are:

- Exploring the opportunities for ambulance services, who are often called to transport the patient, being able to reassure the referrer (often the carer or a junior staff member at a RACF) that a referral is not required.
- Explore alternatives to 'discharge home' for dementia patients admitted to ED due to lack of, or poor, support at home or in the community.

5.4.3 Poor Morbidity and Mortality Rates: Goals

The map also highlights some potentials goals. These include:

- Reduction in unnecessary admissions of dementia patients to ED
- The development of alternatives to immediate transport to ED, by ambulance services.

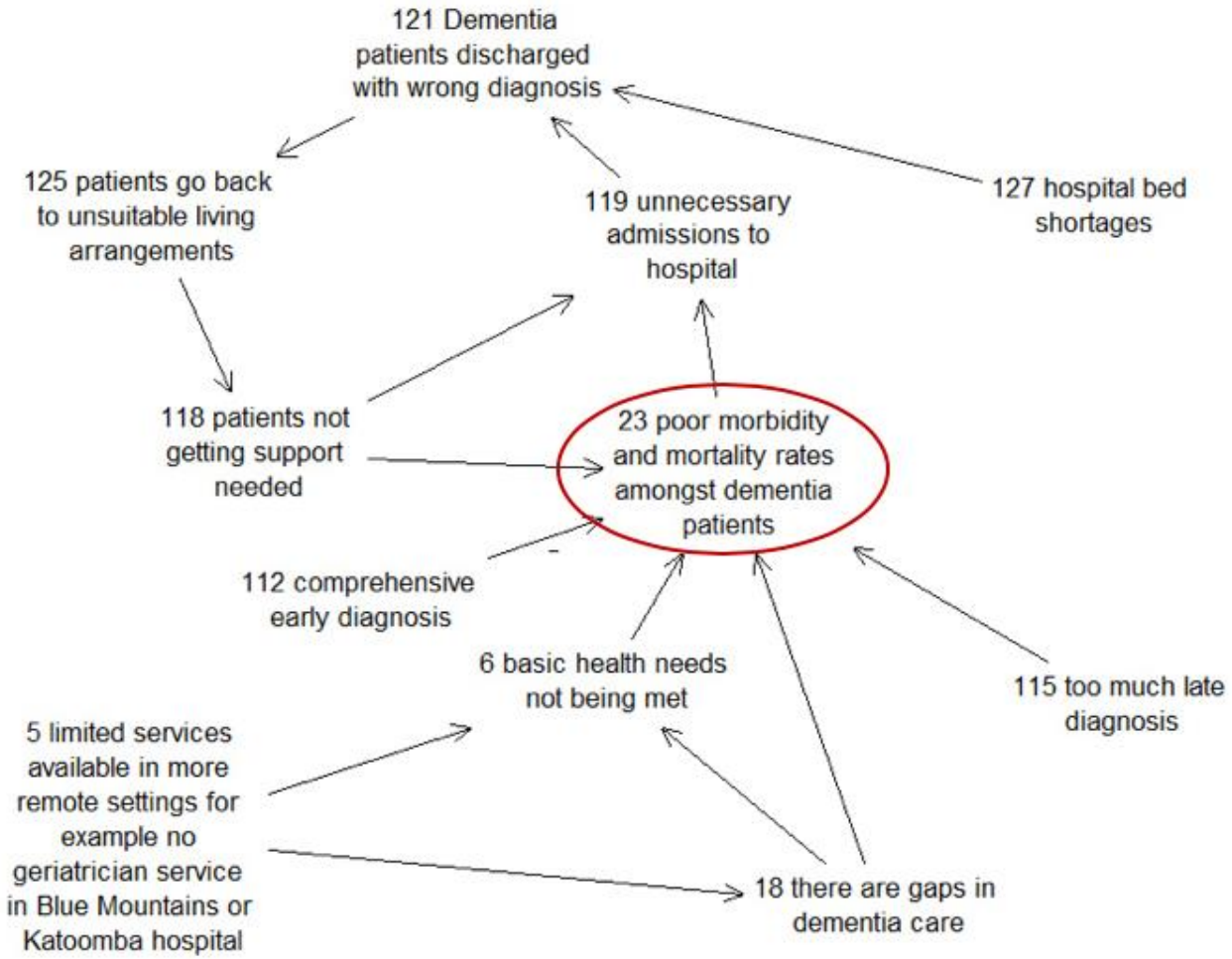


Figure 15: Poor Morbidity and Mortality Rates

5.5 Capability of General Practicioners (GPs)

The cognitive map on the following page (figure 16) illustrates the central role played by GPs and the consequences that result from inadequate knowledge and skills.

5.5.1 Capability of General Practitioners: Mapping The Issues

The central issue raised by this map is that '19 GPs do not recognise dementia'. While many do it is clear that enough do not to make this a significant issue. The two key drives of this issue are firstly, the need to improve the education and information provided to GPs (and other key people such as carers) and secondly to improve peoples' understanding to tackle myths, such as the view that dementia is simply a natural part of ageing (28). The fact that these myths exist, even amongst health professionals, highlights the need for significant efforts to improve understanding of this condition.

The consequences that arise from this issue are errors in diagnosis (83,164 and 26), late diagnosis (115) and service gaps (18).

5.5.2 Capability of General Practitioners: Designing Interventions

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

- A broad public health information and education initiative to improve understanding of the disease.
- A specialist-led education programme for GPS who have a special interest in developing their skills in the diagnosis and care of dementia patients

5.5.3 Capability of General Practitioners: Goals

The map also highlights some potentials goals. These include:

- Having a register of GPs, regionally distributed, who have an interest and additional education and training, in the diagnosis and care of dementia patients
- The establishment of a 'dementia informed and supportive' region.

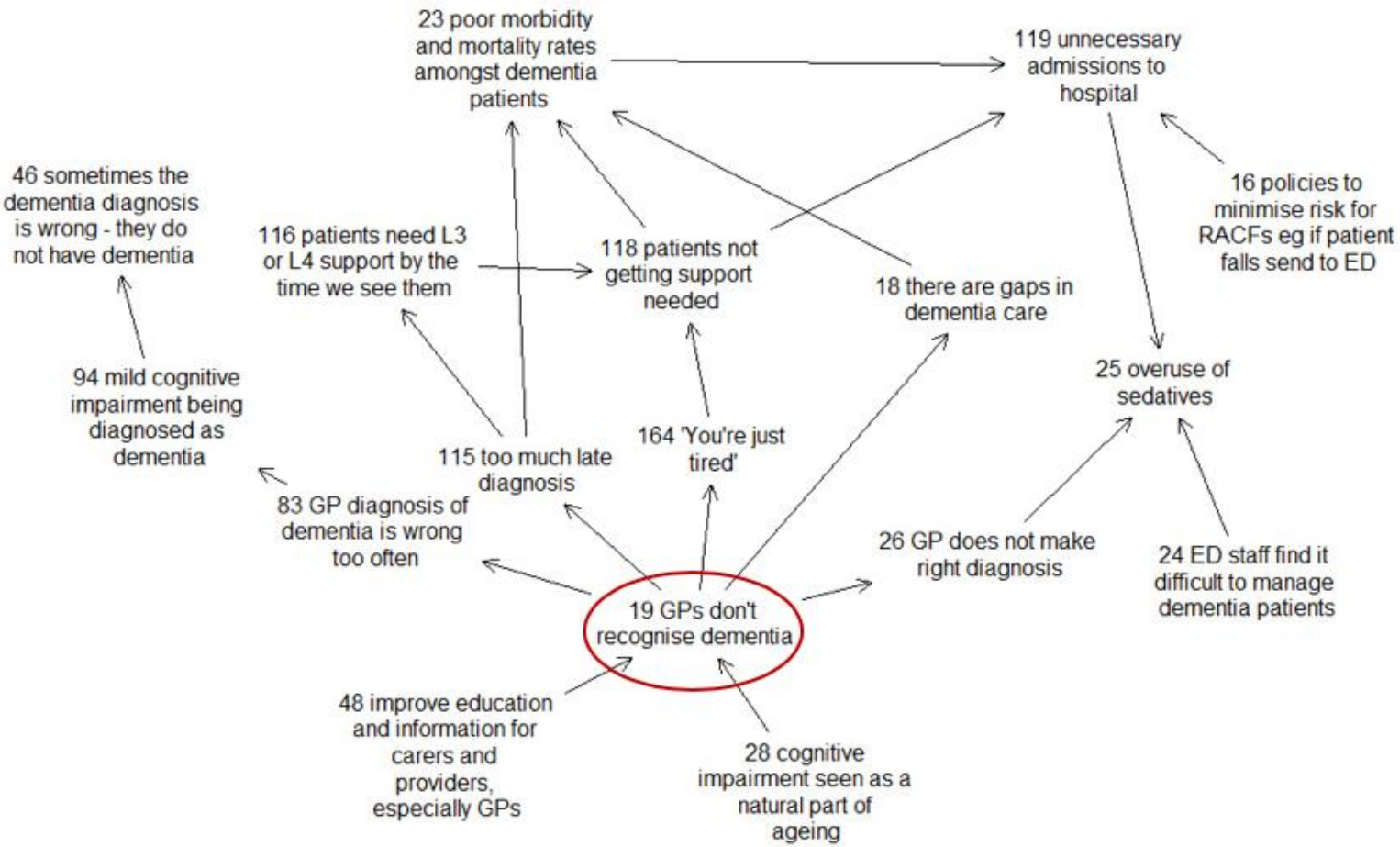


Figure 16: General Practitioners

5.6 Equity

The cognitive map on the following page (figure 17) illustrates the inequities that exist in dementia care.

5.6.1 Equity: Mapping The Issues

Equity, as illustrated in this map covers a number of key areas. Regional inequities highlights the problems for those patients and carers who are not close to Nepean hospital. As in many regions the further one is away from the specialist centre the more difficult it is to access appropriate services. The lack of geriatrician services at Katoomba is one example of this. The inequities in services for Aboriginal people reflects broader issues of racial injustices, (150 152 and 153), lack of cultural understanding amongst providers (151) and a lack of knowledge about the reality of dementia (148). The third area is in relation to the LGBT community. As one carer put it, 'gay people also get dementia' (175). This reflected his challenges not only associated with his partner, who has early onset dementia, but the fact that he is generally the only gay person in the service or support group. This only adds to the stress and challenges he already has to face.

5.6.2 Equity: Designing Interventions

The interventions that arise out of the map are in two key areas:

- The development of new services that do not exist or are not readily available for people in geographically more remote areas.
- Cultural training for healthcare providers
- Recruitment programme to support more members of the CALD communities into health services

5.6.3 Equity: Goals

Goals that arise out of the interventions could include:

- A register of Aboriginal healthcare workers who could be brought in to support the diagnoses and care of Aboriginal patients.
- Establishment of managerial and clinical group to explore possible interventions to ensure that a better regional distribution of available resources.

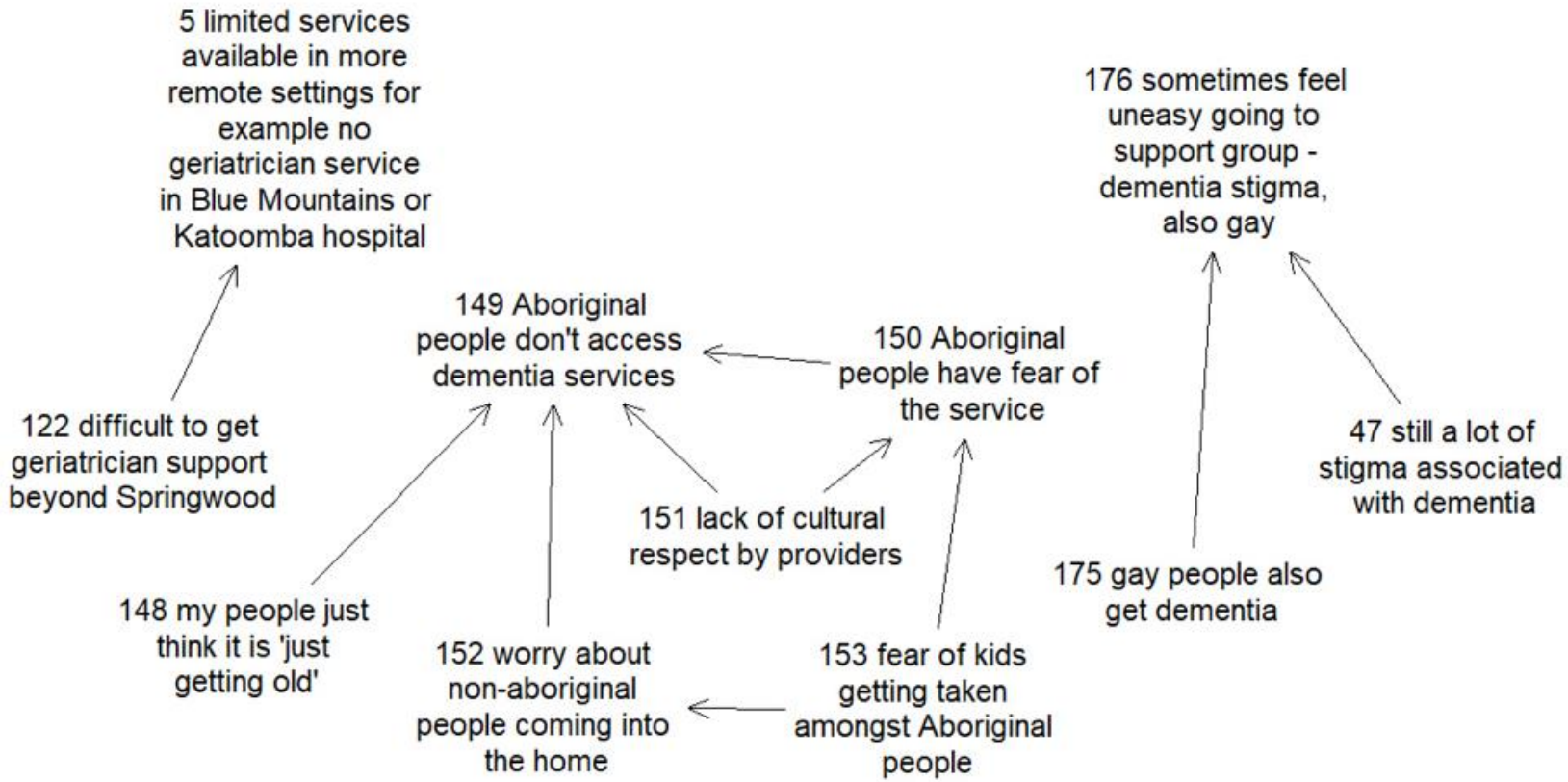


Figure 17: Equity

6. INTERVENTIONS

6.1 Analysis of Issues Maps

The following table summarises the potential interventions that arise out of the issue maps;

Early Diagnosis	1. Improve access to specialist services, including geriatricians. 2. Improve the links between geriatricians and GPs. 3. Enhance the training, education and/or support for GPs, to improve their ability to diagnose and communicate the results of that diagnosis to patients and their carers.
Service Gaps	1. Undertake a detailed review of current services and an explore of whether or not there is a case for a geriatrician service at Katoomba, a unit to manage severe dementia, and step-down service. 2. Undertake a survey of the support needs of patients and carers to explore how those can be met with current and reconfigured services. 3. Improve the referral protocols from GPs to specialist services.
Poor Morbidity and Mortality Rates	1. Exploring the opportunities for ambulance services, who are often called to transport the patient, being able to reassure the referrer (often the carer or a junior staff member at a RACF) that a referral is not required. 2. Explore alternatives to 'discharge home' for dementia patients admitted to ED due to lack of, or poor, support at home or in the community.
Capability of General Practitioners	1. Undertake a broad public health information and education initiative to improve understanding of dementia. 2. Support the development of a specialist-led education programme for GPs who have a special interest in developing their skills in the diagnosis and care of dementia patients.

Equity	1. The development of new services that do not exist or are not readily available for people in geographically more remote areas. 2. Cultural training for healthcare providers. 3. Recruitment programme to support more members of the CALD communities into health services.

6.2 Workshop Participants: Potential Interventions

In addition to the interventions that arise from an analysis of the issues maps workshop participants also brainstormed a number of potential interventions. These reflect the issue maps but are at a more specific, operational level and are grouped into four key themes:

Information and Education	1. Lifting profile and reducing stigma of dementia 2. Open 'pop-up shops' containing dementia information 3. Provide better education for carers, GPs and RACFs 4. Hold CPDE evenings for GPs 5. Utilise GP registrars and training organisations to inform and influence dementia education 6. Improve GP on My Aged Care 7. Hold public information evenings 8. Take on advocacy and education role
Carer Support	1. Improve the availability of residential respite for carers
Connections	1. Engage more with community groups such as Rotary 2. Improve relationships between GPs and geriatricians 3. Develop dementia health pathways, referral guidelines 4. Provide early referral to a memory clinic
Enhancing Current Services	1. Provide rapid response for in RACFs for BPSD and DBMAS 2. Increase telehealth services 3. Improve access to level 4 services 4. Provide high acuity unit for BPSD 5. Improve utilisation of General Practice workforce 6. Provide more equitable access to geriatricians who have dementia as a specialty

6.3 Workshop Participants: Prioritised Interventions

Unfortunately this exercise was not able to be completed in the time available. However the workshop participants did decide on some high priority interventions, to focus on. These were:

- Improved case management
- Improved use of Advance Care Planning
- Development of a protocol and care plan for RACFs for post-fall patients
- Counselling and support for carers
- Opening pop-up shops
- Education for GPs
- Improve screening and diagnosis of dementia

7. Moving Forward

In recommending next steps we are aware that the previous section outlines a large number of possible interventions, all of which are relevant and focused on improving dementia care in the region. However, not everything can be undertaken together and no single intervention is going to resolve the issues discussed. In response to this abundance of potential opportunities for action we would recommend two key foundations upon which to build a future strategy. These are:

1. Focus on building capability, especially in the early diagnosis of dementia, within primary care teams led by, but not solely undertaken by the general practitioner.

2. Adopt a regional approach that focuses on addressing service gaps at the same time as building a health system that is supportive of good dementia care.

These are discussed in more detail below.

7.1 Building the Capability of Primary Care

The poor quality of diagnosis of dementia in primary care is not unique to the Nepean Blue Mountains Region and many people with dementia, especially in its early stages, are not being diagnosed[17]. However as some researchers note;[18]

"…90% of people with dementia can be quickly and competently assessed and supported in primary care *in collaboration with secondary care*." *[my emphasis]*

However, to achieve this improved diagnosis it is not sufficient to focus on the primary care team alone. As the research has shown there are a number of wider, systemic factors making diagnosis difficult. These include, barriers put up by the patients and their caregiver; misinterpreting or denying symptoms, being fearful of stigmatisation, believing that therapy is not effective and being fearful of being sent to a RACF or similar. They also include system barriers in primary care such as funding models, limited availability of specialist advise and the time available for each patient, especially given that many older patients come with a range of co-morbid conditions. They also include physician barriers; they may fail to recognise symptoms, are uncertain in their diagnosis, fearful of stigmatising patients, and hold a belief that diagnosis will not lead to any therapeutic gain.

[17] Dungen, van den, P., et al. (2012). The accuracy of family physicians' dementia diagnoses at different stages of dementia: a systematic review. Int J Geriatr Psychiatry, 27(4), 342-354.

[18] Benbow, S., M, Jolley, D., & Greaves, I., C. (2015). Improving diagnosis of dementia in primary care. Progress in Neurology and Psychiatry, January/February.

The clinicians we talked with all agreed that improved diagnosis in primary care was desired and that it was a feasible goal to work towards. In addition, there has been research exploring quality indicators that can be used to support and assess diagnosis and management in primary care,[19] so the tools do exist to support such a goal.

So, while there does need to be a focus on improving the capability of primary care, this cannot be achieve by focusing on primary care alone. It is a systemic issue and to be solved needs to be tackled as such.

7.2 Taking a Regional Approach

The nature and interconnectedness of the issues discussed above mean that any successful intervention needs to be informed by a clear 'theory of change' that describes how an intervention will not only improve a specific service, but how it will affect the overall system that is currently delivering services for people living with dementia that are well below what is desired. Thus future commissioning needs to balance investments in specific services with investments in improving the underlying conditions that drive good dementia care. This means avoiding individual, fragmented initiatives and focusing on developing an 'interdependent portfolio of interventions' that are informed by the issues noted above and by the perspectives of community, primary and secondary care.

7.3 Key Recommendations

With a sector that is already under resource pressure, we believe that to tackle the issues discussed in this report the PHN needs to avoid adopting a long list of interventions and focus on tackling a small number of service improvements, while developing the infrastructure needed to support improvement over the long-term that acknowledges the financial and resource constraints that exist.

Thus, our primary recommendation is that the Nepean Blue Mountains PHN, establish a cross-sector leadership group (this could be the Older Person's Consortium) to undertake the following tasks:

1. Undertake to promote and implement a small number of the interventions discussed in section 6 that are *relatively* easy to implement within a defined timeframe yet require co-operation across the sector.

The purpose of this recommendation is to not only achieve some 'quick wins', but to use smaller challenges as an opportunity to bring people across the sector together to work on a common issue. These early projects need to be relatively narrow in scope and time limited.

[19] Perry, M., (2010). Development and validation of quality indicators for dementia diagnosis and management in a primary care setting. J Am Geriatr Soc, 58(3), 557-563.

2. Establish a clinical quality improvement collaborative,[20] possibly linked to the health pathways group, to develop and implement an action plan focused on improving the early diagnosis of dementia in primary care.

Early diagnosis is not only a key identified issue in its own right, but is also a key factor contributing to other issues such as 'poor morbidity and mortality rates' and 'equity'. Research clearly states that while early and effective diagnosis can be done effectively in primary care it can only be done in close co-operation with specialist services[21]. Thus, it provides an opportunity to develop greater cross-sector understanding and co-operation, both of which are needed if dementia care is to improve over the long term

3. Once the above items are underway, support the cross-sector leadership group in developing a longer-term 'portfolio of interventions' that are clearly linked to the issue maps discussed in section 5.

What is known about making significant change at a regional level is that there needs to be a number of interdependent initiatives that provide a coherent package of action targeted at key issues[22]. Furthermore , if they are to be implemented successfully, over time, clinical, community and policy leaders need to work together, being willing to develop priorities for the region that are above and beyond their specific organisational concerns. This is no small task, but it is required, if the hopes and aspirations of those we talked to are to have any chance of becoming a reality.

[20] Cations, M., et al (2018). Agents of change: establishing quality improvement collaboratives to improve adherence to Australian clinical guidelines for dementia care. Implement Sci, 13(1)
[21] Benbow, S., M, Jolley, D., & Greaves, I., C. (2015). Improving diagnosis of dementia in primary care. Progress in Neurology and Psychiatry, January/February.

[22] https://www.rethinkhealth.org/resources-list/the-rethinkers-blog/?sf_action=get_results&_sft_rth_author=tami-gouveia#search-block

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