Cognitive impairment and service use: The relationship between research and policy

A thesis submitted for the degree of Doctor of Philosophy of the Australian National University.

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Lily O'Donoughue Jenkins, December 2017

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Abstract

This thesis examines the association between healthcare service use and cognitive functioning in individuals aged 60 years and over. It examines the association between use of primary and secondary health care services, specifically general practitioners and hospitals, and cognitive impairment.

This thesis uses secondary data from the ANU Personality and Total Health (PATH) Through life study. PATH is a longitudinal health study which examines three age-cohorts residing in the Australian Capital Territory and surrounding regions over 12 years. The PATH study also has a number of sub-studies, one of which is the Health and memory sub-study. This sub-study identifies individuals in the PATH sample who would be clinically classified as having mild cognitive disorder (MCD) or dementia.

Data on health service use has been obtained by linking three administrative datasets to PATH. Data on primary health care usage was obtained from the Medicare Benefits Schedule. Data on secondary health care usage was obtained from the ACT Admitted Patient Care dataset and the ACT Emergency Department Information. From this linkage, we have information on number of general practitioner visits over a year, number of hospital admissions, length of hospital stay and number of emergency department presentations for each consenting participant.

Analysis of general practitioners focused on the impact cognitive impairment had on use over the 12 years of study. Using negative binomial models this analysis found that individuals with MCD visited their general practitioner significantly more than individuals who were cognitively healthy. This use almost doubled when individuals had a comorbid condition of depression or arthritis. Analysis relating to hospitalisation also focused on the association between use and cognitive impairment longitudinally. This analysis found that individuals who were hospitalised had significant declines in particular cognitive tests compared to individuals who were not hospitalised.

This thesis also examined factors which impacted on general practitioner, hospital and emergency department use. Predictors of use were examined for individuals with MCD or dementia compared with cognitively healthy individuals, based on the Andersen-Newman model of health behaviour. Analysis using logistic regression models found that individuals with MCD and dementia had higher usage of all three services compared to cognitively healthy individuals. This study also found that need variables were the strongest predictor of healthcare service use. However, the types of predisposing, enabling and need variables varied depending on the healthcare service (general practitioner, same day hospital, multiple day hospital or emergency department) and whether the individual had MCD, dementia or was cognitively healthy.

The information and findings relating to cognitive impairment and health service use are important for policy and practice. Communication of research to policy makers for the development of policy, termed knowledge translation, is discussed in the thesis. Several important models of knowledge translation are outlined and there is a discussion about how to strengthen the relationship between researchers and policy makers. The thesis concludes with a discussion on future policies and practices to increase early detection and diagnosis of MCD and dementia through prevention and screening in healthcare services.

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Glossary

COGNITION: 1) The act or process of knowing: perception. 2) The product of such a process; thing thus known, perceived etc. Adjective: cognitive.

COGNITIVE DECLINE: Also termed 'age-associated cognitive decline' or 'normal cognitive ageing' is defined by non-pathological declines in cognition. Cognitive decline differs in extent between individuals.

COGNITIVE IMPAIRMENT: Cognitive impairment is when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. With mild impairment, people may begin to notice changes in cognitive functions, but still be able to do their everyday activities. Severe levels of impairment can lead to losing the ability to understand the meaning or importance of something and the ability to talk or write, resulting in the inability to live independently.

PRIMARY HEALTH CARE: At a clinical level primary health care usually involves the first layer of services encountered in health care and requires teams of health professionals working together to provide comprehensive, continuous and person-centred care. Most Australians will receive primary health care through their general practitioner. Primary health care can be provided in the home or in community-based settings, such as general practices. The types of services delivered under primary health care include health promotion, illness prevention, treatment and care of the sick, community development, and advocacy and rehabilitation.

SECONDARY HEALTH CARE: Health services provided by medical specialists and other health professionals who do not have first contact are considered providers of secondary care. These services are usually, but not always, provided upon referral by a primary care physician, for example general practitioners may refer patients to geriatricians for cognitive screening. This includes 'acute care' which is considered short-term treatment of a serious injury or period of illness, usually

relatively urgent (e.g. emergency departments). Secondary health care can also refer to ongoing

services not necessarily provided in the hospital, such as psychiatrists, physiotherapists,

occupational therapists, mental health services and aged care services.

PRIMARY PREVENTION: The promotion of health and the prevention of illness. For example,

immunisation and making physical environments safe.

SECONDARY PREVENTION: The early detection and prompt intervention to correct departures

from good health or to treat the early signs of diseases. For example, cervical screening,

mammography, blood pressure monitoring and blood cholesterol checking.

TERTIARY PREVENTION: Reducing impairments and disabilities, minimising suffering caused by

existing departures from good health or illness, and promoting patients' adjustments to chronic or

irremediable conditions. For example, prevention of disease complications.

List of Abbreviations

ACT	Australian Capital Territory
AD	Alzheimer's Disease
ANU	Australian National University
APC	Admitted Patient Care
APOE	Apolipoprotein E
ARC	Australian Research Council
BEACH	Bettering the Evaluation and Care of Health
BPHQ	Brief Patient Health Questionnaire
CHeReL	Centre for Health Record Linkage
CDR	Clinical Dementia Rating Scale
CRAHW	Centre for Research on Ageing, Health and Wellbeing
CVLT	Californian Verbal Learning test
DSM-V	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
ED	Emergency Department
EDIS	Emergency Department Information System
GDS	Global Deterioration Scale
GP	General Practitioner
KT	Knowledge Translation

KTA	Knowledge to Action
MBS	Medicare Benefits Schedule
MCI	Mild Cognitive Impairment
MCD	Mild Cognitive Disorder
MLK	Master Linkage Key
MMSE	Mini Mental State Examination
mNCD	Mild Neurocognitive Disorder
MRI	Magnetic Resonance Imaging
NHMRC	National Health and medical Research Council
NSW	New South Wales
PATH	Personality and Total Health Through Life Study
POCD	Postoperative cognitive dysfunction
PPN	Project Person Number
RecID	Record Identification number
RTA	Research to Action
SDMT	Symbol Digit Modalities test
SF-12	Short Form Health Survey
WHO	World Health Organization

PART 1.

Chapter 1: INTRODUCTION

1.1 Introduction

Chapter 1 has five main purposes. The first is to introduce knowledge translation; the second is to explain the health care system in Australia; the third is to discuss dementia and healthcare in the local and Australian context; the fourth is to provide the aims and objectives of this research study; and the fifth is to provide an overview of the thesis structure.

1.2 Knowledge Translation

The transfer of research findings into health practice has been described as a slow and haphazard process (Graham et al., 2006). This could result in patients not being provided with treatment proven to be beneficial, or being exposed to potentially ineffective or harmful treatment. These situations in turn result in inefficient use of limited health care resources. Black (2001) and Marshall (2014) argue that research still has little influence on health services policy or on practice. However, there is now agreement that research can make a significant contribution to policy and resolving the emerging challenges in health care (Centre for Informing Policy in health with Evidence from Research, February 2014). The range of activities or strategies used to disseminate research evidence to policy makers or practitioners is termed 'knowledge translation.' A definition of knowledge translation is provided in Chapter 2 and a detailed discussion on the process of knowledge translation is provided in Chapter 4.

1.3 Health Systems in Australia

Australia's health system is a complex web of services, providers, recipients and organisational structures (Australian Institute of Health and Welfare, 2014). In this thesis a health system is defined

as all the organisations, institutions and resources whose primary purpose is to promote, restore or maintain health (World Health Organization, 2000). According to the World Health Organization (2000) health systems should respond well to what people expect ('goodness') and to everyone, without discrimination ('fairness'). Health providers within the health system, such as medical practitioners, nurses, hospitals and clinics, provide a range of services across many levels, from public health to primary health care, emergency health services, hospital-based treatments, rehabilitation and palliative care. This thesis focuses on two types of health care practices- primary care and hospitals, including hospital emergency departments, in the capital city of Australia.

In Australia, primary health care is usually a person's first point of contact with the health system (Keleher, 2001). Primary health care is most often provided outside the hospital system. It is primarily delivered through privately-provided general practice, funded largely on a fee-for-service basis supported by patient access to Medicare rebates (Australian Institute of Health and Welfare, 2014; Russell et al., 2013). However, nurses, allied health professionals, midwives, pharmacists, dentists and Aboriginal health workers are also considered primary health care providers (Department of Health, 2013). The types of services delivered by primary health care include health promotion, prevention and screening, early interventions, treatment and management. Services may be targeted to specific populations, such as older people, and target specific health and lifestyle conditions, such as mental health, obesity and diabetes (Department of Health, 2013).

Having good primary health care systems in place is the most effective way to produce better health outcomes, improve health equity and respond to social expectations (World Health Organization, 2008). However, primary care across Australia has had difficulties responding effectively to changing pressures (e.g. demographic change, changes in burden of disease, emerging technologies and changing clinical practice), and coordinating within and across the elements of the broader health system to meet the needs of an individual patient (Department of Health, 2013).

Secondary health care services in Australia usually do not have first contact with the patient, most require a referral from a primary care professional to provide services, or are provided in a hospital setting (ACT Health Directorate, 2011). Hospital services in Australia are provided by both public and private hospitals. Public hospitals are funded by the state, territory and Australian government, and managed by state and territory governments. Private hospitals are owned and operated by the private sector. Private hospitals are mainly funded by private health insurance and out-of-pocket payments by patients (Australian Institute of Health and Welfare, 2017). Hospital emergency departments are a critical component of hospitals and the health system. They provide care for patients who have an urgent need for medical or surgical care and, in some cases, provide care for patients returning for further care, or waiting to be admitted (Australian Institute of Health and Welfare, 2014). Due to the rise in the ageing population and rates of chronic disease there is an increasing demand for hospital services. In public hospitals, there is a gap between the services required and the services available, resulting in long waiting times for elective procedures and queues for treatment in emergency departments (Duckett, 2016). High rates of return visits to emergency departments and adverse outcomes after hospital admission, including declines in cognition amongst older patients, suggest that current procedures in the healthcare system, such as no comprehensive inpatient discharge and lack of timely follow-up by healthcare providers, do not meet the chronic and underlying needs of many older patients (Brennan, Chan, Killeen, & Castillo, 2015; Karam, Radden, Berall, Cheng, & Gruneir, 2015; Lowthian et al., 2016).

Given the challenges faced by primary and secondary health care services new models of care and different ways of providing services are required (ACT Health Directorate, 2011). New ways to manage chronic disease and keep people out of hospital through health promotion, illness prevention and self-management need to be developed, with changes based on robust scientific evidence together with people's expectations of health and health care for themselves, their family and their society (World Health Organization, 2008). The World Health Organization (WHO) has argued that researchers and policy makers should work together to ensure that innovations for

health care services are policy relevant, fully implementable and, if proven to be effective and cost-effective, capable of being applied to scale (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016).

1.4 Dementia and Healthcare in the Local and Australian Context

One health priority in Australia and globally is the need to improve care for people with dementia. It is currently estimated that more than 353,800 Australians living with dementia and this is projected to increase to 900,000 people by 2050. This thesis uses data from individuals who reside in the Australian Capital Territory and surrounding regions. In 2014, it was estimated that 4,100 people in the Australian Capital Territory (ACT) are living with dementia. This number is likely to rise to approximately 5,200 by 2020 - an increase of 43% over 10 years (ACT Health Directorate, 2016). Dementia is the single greatest cause of disability in older Australians aged 65 years and over and the third leading cause of disability burden overall (Australian Institute of Health and Welfare, 2012). In 2016 the total direct health and aged care system expenditure on people with dementia was estimated to be $8.8 billion, rising to $9.1 billion in 2017 (Brown, Hansnata, & La, 2017).

Provision of services for people with cognitive impairment has a significant impact on the health care system. For example, in the ACT alone the number of dementia-related hospitalisations more than doubled between 2004-2005 and 2013-2014 and the length of stay was three times longer compared to those without a dementia diagnosis (12 days vs. 4 days) (ACT Health Directorate, 2016). The health care system is being impacted by the service care needs required by cognitively impaired individuals. Hospitalised patients with cognitive impairment are at greater risk of adverse outcomes than people who do not have cognitive impairment. They are more likely to fall, to experience significant functional decline, and to develop complications such as pressure injuries, delirium, pneumonia and urinary tract infections. Additionally, people with cognitive impairment require more hours of nursing care, are two to three times more likely to die while in hospital (Australian Commission on Safety and Quality in Health Care, 2013; Bail et al., 2013) and have significantly

increased mortality post-discharge than those without cognitive impairment (Freedberg, Dave, Kurth, Gaziano, & Bludau, 2008).

Policy makers at all levels of public and private governance are realising the huge impact that dementia will increasingly have on Australian society (Farrow, 2010). In 2012 Australian Health Ministers designated dementia as the ninth National Health Priority Area and, in 2015, they endorsed the *National Framework for Action on Dementia 2015-2019* (the Framework) to set the direction for improving quality of life for people with dementia, their carers and families, across Australia. The Framework addresses the concepts of a person-centred, ethical and evidence based approach to dementia care and services. The Clinical Practice Guidelines and Principles of Care for people with dementia are written primarily for health and aged care staff who work with people with dementia. According to the guidelines, doctors, nurses and allied health and care workers should receive training in dementia care. This training includes how to communicate clearly with the person with dementia, their carer(s) and family and to provide person-centred care (Guideline Adaptation Committee, 2016).

In light of the increased demand there is a need to strengthen the capacity of the local and national health system to meet the needs of people with dementia, their families and carers, and ensure that they have access to high quality and integrated health care services that suit their care needs. The burden of dementia also needs to be addressed at a population level through effective public health policies, interventions and improved aged care (Australian Institute of Health and Welfare, 2012). Dementia is a difficult and time-consuming condition to diagnose and manage, however, current evidence could be effectively transformed into usable recommendations for both policymakers and physicians (Cook & Rockwood, 2013). To help transform evidence into recommendations, researchers will need to structure their research so that that it has a long-term vision but can also deliver short term outcomes across the domains of prevention, diagnosis, treatment and care (NHMRC, 2015).

Research focused on the early stages of dementia has important implications for population health and future government initiatives. Individuals with any mild cognitive disorder are at an increased risk of developing dementia. The detection and management of mild cognitive impairment in individuals could prevent, delay or decrease the rate of progression to severe dementia. Despite this, there has been very little research on the association between health service use and mild cognitive impairment. Given that this association has implications for future use of health services the author identified the need for more research on this matter. This thesis will provide further information on the association between health service use and mild cognitive impairment with expectations that this matter will receive more research attention in the future.

1.5 Aims and Objectives

This thesis has two main aims. The first is to investigate the association between cognitive functioning and use of primary and secondary health services. The second is to examine the policy implications of these research findings and critically analyse the process of translating research into policy.

1.5.1 Objectives

The objectives of this thesis, related to the two aims above, are:

1. Analyse the use of general practitioners, hospital admissions and emergency department presentations of people who participate in the Personality and Total Health (PATH) Through Life Study and how this use is associated with cognitive impairment and cognitive decline (Aim 1);

2. Analyse factors that may predict the use of these three health services by PATH participants, based on the Andersen Newman model (Aim 1);

3. Examine the different models and frameworks of knowledge translation (Aim 2);

4. Examine the barriers and enablers of knowledge translation and provide some recommendations to both policy makers and researchers of ways to effectively translate research into policy (Aim 2);

5. Understand the complexities of the policy making process and the dissemination of academic research to policy makers by participating in action research, including evaluation of how policy makers apply research and how research and policy connections are facilitated via undertaking a secondment (Aim 2);

6. Critically analyse the policy implications of these research findings, including screening for cognitive impairment, prevention strategies and the provision of appropriate services (Aim 2).

1.6 Presentation of Thesis

This thesis is presented as a combination of traditional and publication format. It comprises a combination of conventional written chapters, presented as typescript, and publications that have either been published or submitted for publication and manuscripts prepared for publication.

In this thesis there are five papers presented. Paper 1 and 2 focus on how research is translated to policy (knowledge translation). The other three are original empirical papers which examine the association between health service use and cognitive impairment or decline. These papers are complemented by other chapters or sections which provide additional information to that provided in each paper.

1.7 Thesis Structure

This thesis contains 9 chapters divided into three parts. Part 1 is an introduction, including three chapters. Chapter 1 introduces the thesis and describes its aims, objectives and structure. Chapter 2

contains a critical review of literature examining cognition and health service use. It also provides an introduction to knowledge translation and a description of mild cognitive impairment and its progression to dementia. The chapter then provides a summary of the current literature regarding general practitioner use, hospital use and cognitive impairment. Chapter 3 provides an account of the data sets and methodology used throughout this thesis. The focus within this chapter is on the linkage of three datasets, including ethical issues of data linkage.

Part 2 discusses the process of knowledge translation, including barriers and facilitators of knowledge translation and the relationship between researchers and policy makers. This part is comprised of only one chapter, Chapter 4, which includes two manuscripts, one on how evidence is evaluated and the other on the use of secondments as a tool to increase knowledge translation between policy makers and researchers. This chapter also provides an overview of seven different knowledge translation frameworks.

Part 3 provides research on use of health services which could be used to inform policy. It discusses the use of primary (general practitioner), and secondary (hospital and emergency department) health care services and the association with cognitive impairment. Part 3 is comprised of five chapters (Chapters 5 to 9). Chapter 5 includes a manuscript which examines the use of general practitioners by people with any mild cognitive disorder. Chapter 6 builds on the previous chapter by including a manuscript which discusses the association between hospital admission and cognitive impairment. Chapter 7 discusses the predictors of healthcare service use (GP visits, hospital admission and emergency department presentations) and its association with cognitive impairment. This chapter includes a manuscript which analyses the predictors of health service use in people with mild cognitive disorder compared to individuals who are cognitively healthy. Chapter 8 discusses the policy implications of health service use research, including the use of screening for cognitive impairment in hospitals and GP clinics. Finally, Chapter 9, provides concluding remarks of the thesis and suggestions for future research.

1.8 Summary

This chapter has provided an introduction to the thesis, including a background on knowledge translation, health care systems in Australia and dementia in the local and Australian context. It presented the aims and objectives of the thesis before concluding with the overall thesis structure.

1.8 Summary

Chapter 2: LITERATURE REVIEW

2.1 Introduction

The previous chapter provided an overview of the thesis structure and content. In this chapter I discuss the existing research on health service use and cognitive impairment. This chapter begins by explaining the concepts of knowledge translation, mild cognitive impairment and progression to dementia. It is important to explain these concepts as this thesis argues that policies regarding dementia and mild cognitive impairment should be based on scientific research. It then discusses the research on general practitioner and hospital use and their association with cognitive impairment. This chapter will then discuss the possible determinants of healthcare service use and their interaction with cognitive function. The chapter concludes with identified gaps in the research and how this study will provide foundational information to fill those gaps.

2.2 Knowledge Translation

2.2.1 What is Knowledge Translation?

In the last 20 years there has been a push for evidence based policy making (Carey & Crammond, 2015). The process of disseminating academic research to policy makers to use in the development of policy is often referred to as 'knowledge translation' (KT). Other terms that have been used to describe all or part of this process include knowledge transfer, knowledge exchange and research utilisation (Graham et al., 2006). A commonly used definition of KT in the health context comes from the Canadian Institutes of Health research, which describes it as "*a dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products, and strengthen the health care system. This process takes place within a complex system of interactions between researchers and knowledge users which may vary in intensity, complexity and level of engagement depending on the*

nature of the research and the findings as well as the needs of the particular knowledge user"
(Canadian Institutes of Health Research, 2005; Graham & Tetroe, 2009).

The process of KT involves many activities and practices, including producing synthesised research aimed at informing policy, writing plain language summaries of findings and spending time with users to understand the policy context and research needs (Jacobson, Butterill, & Goering, 2004a). The KT process is discussed in more detail in later chapters, with different frameworks and the barriers and enablers of KT described in Chapter 4.

2.3 Mild Cognitive Impairment and Dementia

2.3.1 What is Mild Cognitive Impairment?

There are many definitions and terms in used in the literature to describe cognitive impairment that is not dementia. Neuropsychological definitions use normative data to define impairment in a particular cognitive domain. For example, 1.5 standard deviations below the mean for age is often considered impaired. Clinicians often use screening instruments, such as the Mini-Mental State Examination, to identify cognitive impairment, however, these instruments may have insufficient sensitivity to detect mild cognitive impairment (Mitchell, 2009).

In the older population, cognition can be seen as a continuum of states ranging from normal to mild cognitive impairment (MCI) to dementia. This continuum is depicted in Figure 1. This thesis refers to cognitive range, from MCI to dementia, as 'cognitive impairment.' It is normal for cognition to slightly decline with age. Executive function, learning and memory are three cognitive domains that commonly change and which can impact on an individual's independence and quality of life (Williams & Kemper, 2010). Individuals who are defined as normal are those whose memory and day-to-day functioning is about the same as others of the same age (Chertkow et al., 2007) or whose cognition is greater than expected for an individual's age and education level (McDonald, 2011).

MCI, termed mild neurocognitive disorder (mNCD) by the Diagnostic and Statistical Manual of

Mental Disorders (DSM-5), is when individuals begin to show declines in cognition which is beyond

normal impairment but not severe enough for a dementia diagnosis (Petersen, 2004). A similar term

is 'cognitive impairment no dementia'. Cognitive impairment no dementia includes people who

meet the criteria for MCI as well as others who are cognitively impaired but do not meet all the

criteria for MCI (Petersen, 2007; Roberts & Knopman, 2013).
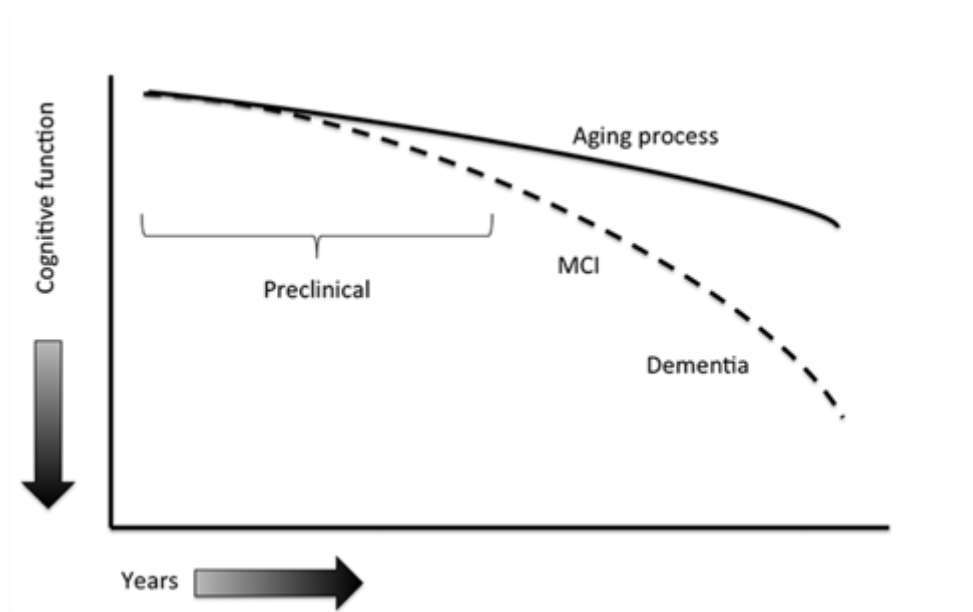
Figure 1. The continuum of cognitive functioning

ADAPTED FROM "TOWARD DEFINING THE PRECLINICAL STAGES OF ALZHEIMER'S DISEASE: RECOMMENDATIONS

FROM THE NATIONAL INSTITUTE OF AGING-ALZHEIMER'S ASSOCIATION WORKGROUPS ON DIAGNOSTIC GUIDELINES

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Most individuals who are diagnosed with MCI fall between 1.0 to 1.5 standard deviations below

norms on memory tests (Chertkow et al., 2007). MCI can be measured using neuropsychological

tests or clinical diagnostic criteria such as the Winblad or Petersen criteria (Petersen, 2004).

However, it is commonly classified according to two severity rating scales- the global deterioration

scale (GDS) and the clinical dementia rating scale (CDR) (Gauthier et al., 2006). The GDS is a 7-stage

scale, ranging from normal (stage 1) to severe dementia (stage 7), with MCI categorised as stage 3.

The CDR is a single numeric score based on an individual's ability in areas of memory, orientation,

social and functional activities and hobbies (Chertkow et al., 2007). The scores range from normal

(CDR=0) to questionable dementia or MCI (CDR= 0.5) to stages of dementia (mild dementia CDR= 1,

moderate dementia CDR= 2, severe dementia CDR= 3) (Petersen, 2004). Although these scales are

useful for describing individuals at the various levels these rating scales cannot fully describe the

syndrome of MCI (Gauthier et al., 2006). For example, an individual could be categorised at stage 3

of GDS, or stage 0.5 on CDR, and either have MCI or meet the diagnostic criteria for mild dementia

or Alzheimer's Disease (AD), which is considerably different from MCI (Chertkow et al., 2007;

Petersen, 2004). CDR scores do not correspond well with MCI, except when the individual has more

severe MCI (Woolf et al., 2016).

MCI is estimated to be prevalent in 5-29% of the total population and is predicted to climb with

the increased longevity of the population (McDonald, 2011). MCI becomes more prevalent with age,

with about 25-40% of individuals aged 70 years and over having pathological signs of MCI (Carrillo et

al., 2009). There is a large amount of research that has tried to identify risk factors associated with

transitioning from normal ageing to MCI and dementia in late life. Genetic and biological factors

identified include older age and carrying the Apolipoprotein E genotype (APOE) which contains ε4

allele (Albrecht et al., 2015; Lim et al., 2015; National Institute on Aging/Alzheimer's Association

Working & Relkin, 1996). Certain health factors place individuals at a higher risk of cognitive

impairment. Some of these health factors include: suffering from hypertension, a history of stroke,

cancer or diabetes, hyperlipidemia, chronic renal failure, vitamin B12 or D deficiency, testosterone

deficiency, having a disability, depression, anxiety and neuroticism (Anstey et al., 2012; Baumgart et

al., 2015; Etgen, Sander, Bickel, & Forstl, 2011). It has also been found that changes in functional

biomarkers, such as muscle strength, cardiovascular health, pulmonary function and body

composition, are linked to cognitive impairment (McDonald, 2011). Finally, lifestyle factors such as

hazardous alcohol consumption or abstaining from alcohol, antidepressant use, smoking, physical inactivity and a high-fat or high-calorie diet are all risk factors (Anstey et al., 2012). High and continued education has been shown to be protective of cognitive impairment (Sattler, Toro, Schönknecht, & Schröder, 2012; Zahodne, Stern, & Manly, 2015).

According to conventional diagnosis MCI is classified into amnestic and non-amnestic forms (Valenti et al., 2015). Amnestic MCI is characterised by significant impairment in memory but other cognitive capacities and functional activities remain intact. Non-amnestic MCI is characterised by declines in functional activities not related to memory, such as use of language, attention or visuospatial skills (Petersen, 2011). These two subtypes can then be divided into four subgroups according to the presence or absence of deficits in different domains. These subgroups are single or multiple domain amnestic MCI and single or multiple domain non-amnestic MCI (McDonald, 2011; Valenti et al., 2015). These subgroups have distinct aetiologies and paths of cognitive impairment (McDonald, 2011). People with amnestic MCI are more likely to progress to AD than people with non-amnestic MCI (Chertkow et al., 2007). For example, the Sydney memory and Ageing study found that 54% of participants with MCI had amnestic subtype, accounting for concordance between MCI and dementia as 81% of cases were subtyped with probable AD after 6 years (Lipnicki et al., 2016). Research has found that individuals with amnestic multiple domain MCI have more cerebral atrophy and increased mortality compared to single domain amnestic MCI subjects (Whitwell et al., 2007). Non-amnestic MCI patients may have a wide variety of outcomes, however this subtype is considered to be the forerunner of dementias that are not related to AD, such as vascular dementia (Davis & Rockwood, 2004).

The DSM-5 has replaced the term "dementia" with major neurocognitive disorder. According to the updated manual MCI is termed mild neurocognitive disorder (Ganguli et al., 2011). However, as the terms dementia and MCI are commonly used and understood these terms will be used throughout this thesis.

2.3.2 Mild Cognitive Impairment and Progression to Dementia

Longitudinal studies have shown that people with MCI are at an increased risk of developing dementia compared to individuals with no cognitive impairment. The progression from MCI to dementia is estimated to be 5-15% per year (Brodaty et al., 2012; Petersen, 2011) and 19-66% over 3 to 5 years (Alexopoulos, Grimmer, Perneczky, Domes, & Kurz, 2006), whereas, the incidence of dementia in healthy older people is only 1-3% per year (Prince et al., 2016). Longitudinal studies have found that subjects with MCI declined at a greater rate than controls, but not as rapidly as subjects with mild AD (Petersen et al., 1999). However, the rates of progression to dementia are varied (McDonald, 2011) and it is not known why some MCI patients progress to dementia and others do not (Davis & Rockwood, 2004). Rates of progression may vary widely because of the sample analysed (clinical-, community- or population-based) or because of the diagnostic procedure used (Chertkow et al., 2007; Petersen, 2004). For example, the Australian Imaging Biomarkers and Lifestyle Flagship study found that 30% of MCI participants met criteria for AD at 18 months follow-up. However, the MCI cohort in this study was primarily recruited from memory clinics and the private practices of geriatricians, neurologist and psychiatrists who specialise in the assessment of memory disorders, therefore individuals may have already been close to transitioning to an AD diagnosis (Ellis et al., 2014).

Particular factors that also affect the rate of progression to dementia include the subtype of MCI (Alexopoulos et al., 2006; Mitchell & Shiri-Feshki, 2009; Wilson, Leurgans, Boyle, & Bennett, 2011), degree of clinical impairment at presentation, being a carrier of APOE ε4 allele and having certain biomarkers (Petersen, 2011). For example, a meta-analysis found that there was a significantly higher annual conversion rate for multiple-domain MCI (12.2%) and amnestic MCI (11.7%) than non-amnestic MCI (4.1%) (Mitchell & Shiri-Feshki, 2009).

Individuals who are diagnosed with MCI may also remain stable long-term or they may return to normal cognitive ageing over time. Patients who are reclassified as cognitively normal in a follow-up

evaluation are reported as unstable MCI (Forlenza, Diniz, & Gattaz, 2010). Unstable MCI is found in 5-20% of longitudinal samples (Forlenza et al., 2010). In one study about 25% of participants identified as having MCI at baseline reverted to normal ageing at 10 years follow-up (Chertkow et al., 2007). Other studies (Ganguli et al., 2004; Larrieu et al., 2002) have found that up to 40% of people with MCI are diagnosed with normal cognitive functioning at follow-up, and a significant minority will have stable cognitive function without progressing to dementia (McDonald, 2011). However, individuals who revert to normal cognition have a higher risk of progressing to MCI or dementia at a subsequent evaluation compared to those who never had MCI (Koepsell & Monsell, 2012; Lopez et al., 2012). Studies indicate that a higher frequency of people with MCI remain in MCI stage or progress to dementia than revert to normal cognition (Roberts & Knopman, 2013). It has also been shown, by the presence of neurofibrillary tangles, that some MCI subjects are showing the earliest stages of AD (Chertkow et al., 2007). As such, the MCI stage may be the best time to intervene with preventative therapies (Massoud et al., 2007).

2.4 General Practitioner Use

2.4.1 Use of General Practitioners and Cognitive Impairment

It is important to examine the association between general practitioner (GP) use and cognitive impairment in older adults. Individuals with MCI may use more health services and have more comorbid conditions than individuals who are cognitively healthy.. In 2014-15 there were more than twice as many Medicare claims for unreferred GP attendances per person for those aged 65 years and over compared to those under 65 (4.4 compared to 10.1) (Australian Institue of Health and Welfare, 2017). The Bettering the Evaluating and Care for Health (BEACH) study found that in 2015-2016 Australians aged 65 years and over had an average 88% more GP encounters, 102% more problems managed and 108% more medications prescribed or supplied compared to people aged 45-64 years (Britt et al., 2016). Although older people have a higher usage of these services there

has been little research specifically examining GP use by patients diagnosed with MCI. Research on the use of GP services by MCI individuals is based on international samples and results are varied. Prevalence rates of MCI among GP patients aged 60 years and over is approximately 15%-30% (Artero, Petersen, Touchon, & Ritchie, 2006; Callahan, Hendrie, & Tierney, 1995; Juncos-Rabadán et al., 2014; Luck et al., 2007; Petersen et al., 2014). Studies have found that approximately 50-60% of cases with cognitive impairment remain undiagnosed (Lang et al., 2017; Ollerenshaw, Wong Shee, & Yates, 2018).

Some previous research that has examined cognitive impairment, from mild to severe, has found that cognitive impairment is associated with an increase in health services usage (Pavon, 2002). Several studies have found that individuals with any cognitive impairment visited their GP or used other health services significantly more than those with no cognitive impairment (Callahan et al., 1995; Fowler et al., 2012; Roelands, Van Oyen, Depoorter, Baro, & Van Oost, 2003). Other studies have looked at the health service use of participants before they were diagnosed with dementia. Ramakers et al. (2007) found that 5 years prior to dementia diagnosis participants had more contact with their GP than controls. The difference in GP use between preclinical dementia participants and controls became more pronounced one year before diagnosis. Preclinical dementia participants had an average of 6.6 visits per year whereas controls only had 3.8 visits. Three other studies (Albert, Glied, Andrews, Stern, & Mayeux, 2002; Eaker, Mickel, Chyou, Mueller-Rizner, & Slusser, 2002; McCormick et al., 2001) also found that people with dementia had more contact with their GP in the 1 to 2 years prior to their diagnosis compared to those who were cognitively healthy. Furthermore, studies found that after being diagnosed with dementia individuals continue to use more primary health care services and have higher annual medical costs than those who remain free of the disease (Albert et al., 2002; Geldmacher et al., 2013b; Richards, Shepherd, Crismon, Snyder, & Jermain, 2000; Taylor & Sloan, 2000a; Zhao, Kuo, Weir, Kramer, & Ash, 2008).

Increased usage of GPs in MCI patients could be due to a range of factors. Although most individuals with MCI are able to live independently (Alzheimer's Australia, 2008), they may have significantly more difficulty with daily activities (Comijs, Dik, Aartsen, Deeg, & Jonker, 2005). An increase in contact frequency may be due to patients experiencing symptoms relating to their decline in cognition and physical functioning (Ramakers et al., 2007). Research has found that GP visits significantly increased if the patient with cognitive impairment also had depressive symptoms or comorbid conditions, such as diabetes, stroke or hypertension (Fowler, 2013; Griffith et al., 2016; Luck et al., 2007; Ramakers et al., 2007), with the number of comorbidities significantly increasing primary care consultation rates (Browne, Edwards, Rhodes, Brimicombe, & Payne, 2017). These associated factors contribute to MCI patient's higher use of health services (Comijs et al., 2005; Krause, 1996).

Other research, however, has found that the presence of cognitive impairment had no effect on the amount of GP services used (Roelands et al., 2003; Zimmer, Ofstedal, & Chang, 2001). One study found no significant difference in mean annual direct medical costs between MCI and non-MCI patients (Luppa et al., 2008). Other research has found no significant difference in use of primary care services between pre-dementia patients and controls and this remained the same after dementia was diagnosed (Leibson et al., 1999; Philp et al., 1995). Lower cognitive function has been shown to be significantly associated with some healthcare services, such as institutionalisation and contacting a medical doctor for memory complaints, but not associated with GP use (Comijs et al., 2005). Finally, there is research which shows that cognitive impairment is associated with fewer visits to GPs (Walsh, Wu, Mitchell, & Berkmann, 2003). Studies have found that after dementia diagnosis patients made significantly fewer visits to a GP than those without dementia (Kasper, 1995; Leibson et al., 1999; McCarten, Anderson, Kuskowski, Jonk, & Dysken, 2010; McCormick et al., 2001). However, this could be due to clinician's making more visits to dementia patients in nursing homes or patients seeing specialists instead (Leibson et al., 1999).

2.4.2 Importance of General Practitioner Use

GPs play a fundamental role in the detection, monitoring and treatment of cognitive impairments. Patients with an increased risk of dementia or with MCI often go to their GP for a medical problem which is unrelated to memory or cognition (Hanzevacki, Ozegovic, Simovic, & Bajic, 2011). Some patients will contact their GP because they are concerned about their cognitive health and have a family history of dementia or suffer from depression or psychosocial stress (Knopman, Boeve, & Petersen, 2003). In these circumstances GPs can provide opportunities for disease prevention and health promotion to patients who are at risk of developing MCI or dementia (World Health Organization, 2008).

GPs are often the first point of contact when individuals, or their relatives, begin to show signs of memory impairment (Fowler et al., 2012; Ramakers et al., 2007). GPs have often known their patients for a long period of time so they may be able to detect early signs of MCI and monitor changes in cognition or behaviour (Hanzevacki et al., 2011; Löppönen, Räihä, Isoaho, Vahlberg, & Kivelä, 2003; Ramakers et al., 2007).

Patients with MCI tend to have more medical problems (Callahan et al., 1995; Fowler et al., 2012; Luck et al., 2007; Ramakers et al., 2007) and psychiatric symptoms (Apostolova & Cummings, 2008; Geldmacher et al., 2013b; Luck et al., 2007; McDonald, 2011; Regan & Varanelli, 2013; Yates, Clare, & Woods, 2013). For example, it has been found that depression is present in up to 60% of MCI patients (Chertkow et al., 2008). These medical problems may exacerbate cognitive dysfunction and contribute to the rate of decline (Fowler, 2013). The GP is important in these circumstances as they can evaluate patients' cognitive state, as well as provide treatment for and monitor comorbid conditions. Furthermore, GPs can identify and treat potentially reversible causes of cognitive impairment, such as depression, drug or alcohol abuse, adverse drug effects, and nutritional conditions such as Vitamin B-12 deficiency (Robinson, Tang, & Taylor, 2015; Tripathi & Vibha, 2009).

GPs are largely responsible for deciding when a patient should be referred for specialist assessment and care for dementia (Artero & Ritchie, 2003; Luck et al., 2007).

2.4.3 Economic Cost of General Practitioner Use

Elderly adults mainly visit their GP for health care and, given that the over 65-year-old age group is increasing, the manifestations and complications of MCI and dementia may result in an additional burden on primary care (Ganguli et al., 2004), and an increase in health expenditure.

The annual cost of healthcare services has been shown to be substantially higher for patients with cognitive impairment than for those without impairment (Albert et al., 2002; Zhu et al., 2013). Studies have shown that this higher expenditure is associated with the severity of cognitive impairment - prevalent dementia being associated with significantly higher medical costs compared to individuals with MCI or cognitively normal (Leibson et al., 2015; Ton et al., 2017). For example, it has been shown that a 1-point decrease in Mini-Mental State Examination (MMSE) score is associated with approximately $2,000 greater medical costs and that individuals with an MMSE score between 18 and 23 cost $53,506 more per year than individuals with a score over 24. Research has found that direct medical costs for individuals with MCI are higher than for individuals who are cognitively healthy, however this difference was not statistically significant (Leibson et al., 2015; Luppa et al., 2008). In individuals with AD the cost of healthcare services is noticeably higher in the year prior to diagnosis compared to controls (Geldmacher et al., 2013b).

Research is needed to determine whether the early detection of cognitive impairment would reduce the costs of healthcare services. Although savings may be generated from early detection and treatment, it is unclear whether that would be offset by costs associated with further testing, therapies, management of expensive comorbidities and future long-term care costs (Lin & Neumann, 2013).

The increase in cognitively impaired patients in the population is not only a financial burden but may place pressure on GPs and increase the amount of time they spend with older patients. From

2000 to 2002, 25% of GPs caseload was already with patients aged 65 years and older (O'Halloran & Britt, 2004). As MCI and dementia are age-related disorders then the increase in these disorders may also increase the amount of time GPs spend with older patients thereby increasing their caseload. The UK National morbidity statistics showed that dementia was associated with an annual incidence of 1.6 new patients per GP and 7.4 more consultations (Milne, Culverwell, Guss, Tuppen, & Whelton, 2008). However, the burden that cognitively impaired patients place on GPs may be even greater than predicted due to discrepancies in prevalence between community and clinical populations (Ganguli et al., 2004).

2.5 Emergency Department and Hospital Use

2.5.1 Emergency Department Presentations and Cognitive Impairment

In considering the broader service use context of adults with cognitive impairment, it is useful to review hospital use among older adults more generally. Older adults are 1.5 times more likely to present at an emergency department (ED) than those aged 20 to 64 (Provencher et al., 2016), with attendances by people aged 65 years and over constituting around 20% of attendances in Australia (Australian Institute of Health and Welfare, 2016b). With the growing ageing population, the number of visits older adults will make to ED is expected to increase (Kilshaw & Australian and New Zealand Society for Geriatric Medicine, 2009). Compared to young patients, older adults who visit ED are at increased risk of functional decline and medical complications, have longer lengths of stay in ED, consume more resources, are more likely to be admitted to hospital and have a higher rate of return visits to ED (Hirschman et al., 2011; Lowthian et al., 2011; Lowthian, McGinnes, Brand, Barker, & Cameron, 2015). Even after being seen in ED the needs of older patients often remain unaddressed. For example, approximately 80% of older patients discharged from ED have at least one unaddressed health issue. One study has found that 43.9% of older patients returned to ED at least once within 30 days and 7.5% returned three or more times in six months (McCusker, Cardin,

Bellavance, & Belzile, 2000). Within 3 months of discharge 12.4% of older patients died and 18.3% were hospitalised (Karam et al., 2015).

Approximately 21-42% of older adults who present to ED have some form of cognitive impairment (Carpenter, DesPain, Keeling, Shah, & Rothenberger, 2011; Gagnon-Roy et al., 2018; Gray et al., 2013; Hirschman et al., 2011; Ouellet et al., 2016; Wilber, Lofgren, Mager, Blanda, & Gerson, 2005), whether or not linked to dementia (Provencher et al., 2016). Stephens, Newcomer, Blegen, Miller, and Harrington (2014) found that in nursing home residents MCI was predictive of higher rates of total ED visits compared to people who were cognitively healthy. They also found that the number of ED visits per year without hospitalisation were higher than with hospitalisation. Despite this there is little known about older ED patients with cognitive impairment, specifically MCI (Schnitker, Beattie, Martin-Khan, Burkett, & Gray, 2016).

Research that has examined dementia and ED use has found that people with dementia have a 20-50% higher probability of visiting ED than those without dementia (Clevenger, Chu, Yang, & Hepburn, 2012; Grober, Sanders, Hall, Ehrlich, & Lipton, 2012) and this increases as people with dementia approach end-of-life (Sleeman, Perera, Stewart, & Higginson, 2017). People with dementia are hospitalised more often and have increased odds of returning to the ED within 30 days of an ED visit compared with people who have never had a dementia diagnosis (LaMantia, Stump, Messina, Miller, & Callahan, 2016). Individuals with dementia who seek care from ED have more medical comorbidity, accrue higher ED charges, and die at an accelerated rate in the time after an initial ED visit compared with individuals without dementia (Grober et al., 2012; LaMantia et al., 2016). Adverse events for patients with dementia in the ED include poor health outcomes, such as dehydration, infection and antipsychotic use, and return visits for the same health complaint (Clevenger et al., 2012).

Conditions in ED, such as long wait times, treatment in noisy and congested hallways and lack of daylight, may influence the onset and level of cognitive impairment in elderly patients. For example,

among those found to have some form of cognitive impairment in the ED, 80% had no prior history

of dementia (Hirschman et al., 2011). However, the effects of ED on cognition may be temporary. A

study by Shah et al. (2011) found that of those people identified as being cognitively impaired in ED

only 12% had evidence of impairment at 2-week follow-up. Other factors may contribute to

individual's cognitive impairment prior to ED presentation, such as presence of delirium,

malnutrition, onset of frailty, having multiple comorbidities (Carpenter et al., 2015; Ellis et al., 2014),

decreased mobility (Brown, Kennedy, Lo, Williams, & Sawyer, 2016) or having depression (Ouellet et

al., 2016).

2.6 Hospitalisation and Cognitive Impairment

Cognitive impairment in hospital patients is usually higher than in the general population,

especially in those aged over 85 years (Mecocci et al., 2005). Prevalence rates of cognitive

impairment are estimated to be between 10-35% in patients over 75 years accessing general

medicine services (Joray, Wietlisbach, & Büla, 2004) and over 80% for critical care patients, making it

the most prevalent hospital condition (Freedberg et al., 2008). Research has found that individuals

with cognitive impairment are at an increased risk of hospitalisation. Although this is strongly related

to severe impairment, even people with mild impairment have elevated rates of hospitalisation

(Zimmer et al., 2001). A study based in the U.S by Weiler, Lubben, and Chi (1991) found that

participants with cognitive impairment were almost twice as likely as those without any impairment

to be hospitalised. Another U.S. study (Chodosh et al., 2004b) found a strong association between

high-functioning older persons who had some cognitive impairment and hospital use over a 3-year

period. They found that a decline in verbal cognitive function, suggestive of MCI, was associated

with an increased risk of hospitalisation.

Similar research has also found that those with a dementia diagnosis had higher hospitalisation

rates than those without (Borson et al., 2013) and in a cohort aged 65 years or older those who

developed dementia were significantly associated with an increased risk of hospitalisation (Phelan, Borson, Grothaus, Balch, & Larson, 2012). In this cohort cognitively intact older people were monitored for up to 8 years and it was found that adjusted rates of hospitalisations were much higher for those who eventually developed dementia compared to those who remained dementia free (Phelan et al., 2012). Furthermore, research has found that patients with dementia have significantly more visits to the hospital and emergency room on average per year compared to controls, both before and after their dementia diagnosis (Eaker et al., 2002). A recent study has shown that injury is the most common reason for hospital admission for people with dementia, with majority of injuries (91%) being due to a fall (Harvey, Mitchell, Brodaty, Draper, & Close, 2016).

Studies have also demonstrated that patients with cognitive impairment have a longer length of stay in hospital than those without cognitive impairment (Boustani et al., 2010; Weiler et al., 1991). In one study people with cognitive impairment who did not have dementia were in hospital for an average of 20.6 days compared to 8.7 days for those who are cognitively healthy (St-Hilaire, Hudon, Préville, & Potvin, 2017).

One US study found that participants with AD had a significantly longer length of stay compared to participants that did not have AD (Richards et al., 2000). The AD participants' length of stay was on average 7.2 days, whereas the non-AD patient's length of stay was 6.0 days. Richards et al. (2000) also found that over a one-year period more AD participants had been hospitalised (39.6%) compared to non-AD participants (16.1%). Research has also found that the length of hospital stay can increase if cognitively impaired patients also have delirium (Reynish et al., 2017; Tropea, LoGiudice, Liew, Gorelik, & Brand, 2016). For example, Reynish et al. (2017) found that the mean length of stay was 34.3 days for those with delirium superimposed on dementia compared to 20.1 days for those who had dementia alone.

Service use varies by country and health system so we may find that the association between hospital use and cognitive impairment differs. Most of the research examining the association

between hospital use and cognitive impairment has been conducted internationally, particularly in US. Further research on the association between these two variables is required in order to gain a greater understanding of how cognitive impairment can impact the level of service use, and vice versa, in the Australian setting.

2.6.1 Cognitive Decline and Impairment During and Post Hospitalisation

As discussed above, older people with cognitive impairment are at an increased risk of hospitalisation (Weiler et al., 1991) and longer hospital stays (Richards et al., 2000). However, research has also found that older people who are hospitalised experience some cognitive decline during and after hospitalisation (Mathews, Epperson, & Arnold, 2013). For example, in one study hospitalised patients performed significantly worse on 9 out of 10 cognitive tests than community-dwelling participants, and cognitive impairment was significantly worse in older hospitalised patients than younger ones (Woods, Mark, Pitts, & Mennemeier, 2011).

Cognition may also continue to decline after the patient has been discharged from hospital. One study found that patients 65 years and older had a 2.4-fold increase in the rate of cognitive decline after hospitalisation, even after controlling for illness severity and pre-hospital cognitive decline (Wilson et al., 2012). Another study by Bickel, Mösch, Seigerschmidt, Siemen, and Förstl (2006) found that 61% of patients aged 65 to 85 years who had been classified as MCI in hospital were rated as impaired 3.5 months after discharge. In other studies about 30% of elderly patients declined by more than 1 MMSE point at discharge (Huber & Kennard, 1991) and approximately 20% declined by more than 2 MMSE points (Fitzpatrick et al., 2004). In cognitively healthy adults hospitalisation may affect some cognitive functions but not others. Research has found that post-discharge cognitive impairment is global in nature and commonly affects executive function, attention and episodic memory (Ehlenbach et al., 2010; Wilson et al., 2012).

Cognitive decline after discharge from hospital has been found to occur in 40% (Gruber-Baldini et al., 2003) to over 50% (Chen, Chiu, Chen, Cheng, & Huang, 2011; Cherbuin et al., 2009) of all

patients and may persist until up to 12 months post-discharge. Cognition often improves within one month after discharge (Inouye, Bogardus, Baker, Leo-Summers, & Cooney, 2000) and studies have shown that cognition returns to normal in one year (Lindquist, Go, Fleisher, Jain, & Baker, 2011). However, other studies have shown that 5 to 7.5 years after discharge 42% of patients still had some cognitive impairment, suggesting that there was an improvement followed by a decline (Newman et al., 2001). Whether patients recover from this post-discharge cognitive impairment completely, or if some impairment remains long-term or if it initiates a neurodegenerative-type cognitive impairment is uncertain as no longitudinal study has followed patients over a long period of time (Chen et al., 2011; Mathews et al., 2013).

The pattern and rate of cognitive impairment after discharge (post-hospital decline) may depend on the severity of the patient's medical condition and the length of time the patient stayed in hospital (Wilson et al., 2012). One study identified four possible patterns of cognitive change after hospitalisation (Chen et al., 2011). These four patterns were: 1) worsening then improving, 2) low continuous, 3) start with high cognitive function then decline and 4) start with low cognitive function then decline. These patients had no profound cognitive impairment before hospitalisation and were hospitalised for more than 5 days.

Cognitive impairment is more prevalent and rapid in those who are sicker and who experience a longer stay in hospital (Monk et al., 2008; Wilson et al., 2012). It has also been found that older age and the severity of cognitive impairment before hospitalisation is related to post-hospital cognition (Wilson et al., 2012).

A range of specific hospitalised conditions are associated with cognitive impairment in older patients, including pneumonia (Davydow, Hough, Levine, Langa, & Iwashyna, 2013), heart failure, stroke (Helvik, Selbæk, & Engedal, 2012), physical impairment (Gruber‐Baldini et al., 2003) and surgical procedures (Canet et al., 2003). Particular types of surgery that have been reported to be associated with cognitive dysfunction include carotid endarterectomy, hip arthroplasty, artery

bypass graft and thoracic surgery (Woods et al., 2011) and coronary artery bypass (Newman et al., 2001).

Postoperative cognitive dysfunction (POCD) can result in two patterns- an acute cognitive impairment, referred to as early postoperative delirium, or a later onset, which has more persistent cognitive dysfunction (Terrando et al., 2011). In one study the incidence of cognitive dysfunction in patients over 60 years 1 week after major surgery was 25%, 3 months later it had dropped to 10%. Follow up at 2 years of these affected patients found that most had similar cognitive function as matched controls, however 1% had unresolved cognitive impairment (Fines & Severn, 2006). Patients who undergo surgery and have decline in cognition immediately afterwards are at an increased risk of long-term cognitive impairment and decreases in overall cognitive function (Newman et al., 2001). Monk et al. (2008) found that the prevalence of cognitive dysfunction at 3 months post-discharge was significantly higher in the older patients compared to age-matched controls. POCD is associated with longer length of hospital stay, more comorbidities and higher risk of mortality (Terrando et al., 2011). Monk et al. (2008) found that patients with POCD were more likely to die in the first 3 months, and patients whose cognitive dysfunction remained after three months were more likely to die in the first year after surgery.

Studies examining the incidence of cognitive impairment after coronary bypass surgery found that cognitive impairment occurred in 9% of patients at 12 months and increased to 40-42% at 5 to 7.5 years following cardiac surgery (Evered, 2017; Newman et al., 2001). This trajectory mirrors the pattern demonstrated by previous studies of early decline, recovery and then long-term decline following in-hospital delirium (Inouye et al., 2016). In another study older age, lower education, comorbid conditions and delirium were risk factors for cognitive impairment after cardiac surgery. They found that those with delirium had a larger drop in cognitive function after surgery and significantly lower cognitive function at 1 month and 1 year after surgery compared to those who did not have delirium (Saczynski et al., 2012).

Delirium may result in decreased cognitive function after surgery, however, cognitive impairment is also a risk factor for delirium (Jackson, MacLullich, Gladman, Lord, & Sheehan, 2016). Two-thirds of all cases of delirium are in patients with dementia (Tulebaev, Inouye, & Fong, 2009). Findings from one study suggest that after undergoing surgery with general anaesthesia administered patients with MCI are at an increased risk of postoperative delirium (Sprung et al., 2016). Delirium and cognitive impairment have similar etiologies which may explain the close relationship between the two conditions (Tulebaev et al., 2009).

Long-term cognitive impairment is also common after critical hospitalisation and treatment in intensive care units (Wolters, Slooter, van der Kooi, & van Dijk, 2013). One study found that after discharge from an intensive care unit 64% of patients had some cognitive impairment, but it dropped rapidly to 10% after 1 year. Other research has shown that the risk of patients developing cognitive impairment 1 to 6 years post-discharge from critical hospitalisation was up to 78% (Mathews et al., 2013).

Most studies suggest that critical hospitalisations and treatment in intensive care units are associated with long-term cognitive impairment (Wolters et al., 2013), however, there is evidence that noncritical hospitalisations are also associated with cognitive impairment (Mathews et al., 2013). Noncritical hospitalisation occurs when there is an absence of any one of a list of critical illness diagnosis and procedure codes as defined by the International Classification of Diseases (Ehlenbach et al., 2010). One study examined cognitively healthy individuals, aged 65 years and over, who were admitted to either non-critical or critical hospitalisation. They found that individuals who were hospitalised were at a greater risk of cognitive impairment compared to those who were not hospitalised, regardless of whether it was critical or noncritical. They also found no significant association between time and hospitalisation, demonstrating that the rate of cognitive impairment did not change after either type of hospitalisation. This supports the view that any type of hospitalisation may cause a sudden loss of cognitive function rather than accelerating decline or

being a sign of cognitive impairment. This study provides evidence that there may be many factors common to all hospitalisations that contribute to the risk for cognitive impairment (Mathews et al., 2013).

Although research has shown that there is an association between hospitalisation and cognitive impairment the relationship between them is poorly characterised. Firstly, most of the literature relies on retrospective measurement of cognition before hospitalisation. This makes it difficult to determine whether changes in cognition had a sudden onset or if they were accelerated by the hospitalisation (Mathews et al., 2013). To the authors knowledge there have been no studies that have systematically examined pre-hospitalisation cognition, cognition during hospitalisation and follow-up outcomes post-hospitalisation. Secondly, some studies lack information on factors which may affect cognition, such as reason for admission and medication use. Thirdly, the tests used to assess cognitive impairment differ between studies making comparison difficult as there is no standardisation between the tests. Fourthly, the recruitment of the patients may not be representative of the sample. Patients who feel that they have, or are at risk of, cognitive impairment may elect not to take part in studies, or they may withdraw if they feel that their cognition has worsened. Fifthly, performance in cognitive tests is sensitive to the environment in which the tests are being administered. Factors which may affect results include the mood of the patient at the time and practice effects (Fines & Severn, 2006).   Finally, due to the lack of long-term follow-up in studies it is not clear whether hospitalisation leads to cognitive decline that remains stable after discharge or if it initiates a progressive cognitive impairment (Mathews et al., 2013).

2.6.2 Association between Hospitalisation and Cognitive Decline

The association between hospitalisation and cognitive decline is probably not due to a single cause, but is more likely to be multifaceted and due to a number of interacting factors (Hopkins &

Jackson, 2006). Hospitalisation is often associated with events that could lead to cognitive decline, particularly in older people who have a prolonged hospital stay (Chen et al., 2011).

Delirium is one event that has been shown to increase an individual's risk of cognitive impairment (Delaney, Hammond, & Litton, 2018; Hopkins & Jackson, 2006; Mathews et al., 2013) or accelerate the progression of cognitive impairment (Caplan, Kurrle, & Cumming, 2016). Delirium is a common neurological disorder in older hospitalised patients (Álvarez-Fernandez, Formiga, & Gomez, 2008) which often has a short time course (Fines & Severn, 2006). It is estimated that about 15-31% of older general medical inpatients meet the criteria for delirium (Reynish et al., 2017; Wilson et al., 2012), 15-65% of surgical patients over 65 years (Jackson, Gordon, Hart, Hopkins, & Ely, 2004; Tulebaev et al., 2009) and up to 80% in patients with critical illness (Gunther, Morandi, & Ely, 2008; Tulebaev et al., 2009). However, it is likely that many more patients exhibit sub-syndromal signs of delirium (Rukovets, 2012). The main characteristics of delirium are reduced ability to maintain attention, disorganised thinking, reduced conscience, disorientation, perceptual disturbances, change in psychomotor activity and memory impairment (Gruber‐Baldini et al., 2003). Due to similar symptom profiles delirium is often misdiagnosed as depression or dementia in both in- and out-patient settings (Stroomer-van Wijk, Jonker, Kok, van der Mast, & Luijendijk, 2016; Tomlinson, 2016).

There are several studies that suggest that an episode of delirium during hospitalisation contributes to cognitive impairment after discharge (Wilson et al., 2012). Boustani et al. (2010) found that more than one-third (38%) of patients who were diagnosed with cognitive impairment 2-days after being admitted to hospital had delirium at least once during their hospital stay. Another study found that in older patients delirium was an independent predictor of sustained poor cognitive and functional status one year after discharge (McCusker, Cole, Dendukuri, Blzile, & Primeau, 2001). Severe illness, older age and prehospital cognitive impairment are risk factors for delirium (Holly, Cantwell, & Kamienski, 2013). The prevalence of cognitive impairment in hospital patients with

delirium ranges from 51 to 68% (Jackson et al., 2016; Ryan et al., 2013). This supports the idea that

delirium partially mediates the association between hospitalisation and cognitive impairment

(Wilson et al., 2012).

The association between delirium and cognitive impairment after discharge from hospital has

also been shown in surgical patient populations (Mathews et al., 2013). Delirium that occurred

before or after surgery was associated with persisting cognitive impairment at 1 year in 40% of

patients (Gruber‑Baldini et al., 2003). Lundstrom, Edlund, Bucht, Karlsson, and Gustafson (2003)

found that those with delirium were 3.5 times more at risk of developing dementia 5 years after

their surgical procedure. Other studies have found that the duration of the delirium affects the risk

of cognitive decline. A study of intensive care unit patients found that those with a longer duration

of delirium had worse global cognition and executive function scores at 3 months and 1 year after

discharge compared to those with a shorter duration of delirium (Pandharipande et al., 2013). The

severity of delirium can also increase the odds of developing cognitive impairment by 1.6 times in

intensive care unit patients (Sakuramoto, Subrina, Unoki, Mizutani, & Komatsu, 2015).

Although these studies suggest that delirium is associated with cognitive impairment after

hospitalisation only a proportion of patients who have an episode of delirium go on to experience

cognitive decline. There are other factors that could be contributing to the relationship between

cognitive impairment and delirium. It has been proposed that delirium is part of a stress response,

and it has been found that stress may play a role in the development of both delirium and cognitive

impairment (Mathews et al., 2013).

Stress is a possible risk factor for the development of cognitive impairment, and both physical

and psychological stress are likely to be present during hospitalisation. The psychological stress of

not needed hospitalisation may compound the physical stress of the illness itself (Mathews et al.,

2013). During the hospitalisation process older patients may experience stress as they are faced with

a new environment and find orientation in the hospital difficult (Lindquist et al., 2011). They remain

bed-bound for long periods of time but frequently experience a lack of sleep and reversal of day-night due to disruptions throughout the night (e.g., alarm bells beeping, roommates snoring, and vital signs being checked) and so naps during the day are encouraged to balance these awakenings. As a result, patients may feel stress or delirium due to the hospitalisation process, disruptions in routine and their acute illness (Dasgupta, 2016).

The hospital environment may also impact on individuals who are cognitively impaired. Although patient-centred care is highly recommended for individuals with dementia there are barriers to providing it in the hospital environment. For example, space limitations, a focus on the physical needs of the patient rather than their psychological needs, lack of time due to a stressful acutely changing environment, disruptions due to room changes and lack of staff training (Dasgupta, 2016). Furthermore, studies have found that recognition of dementia in hospitals is poor (Douzenis et al., 2010; Russ et al., 2012; Torisson, Minthon, Stavenow, & Londos, 2012).

Other factors that could contribute to the relationship between hospitalisation and cognitive impairment include surgery and medication use. The risk of prolonged cognitive impairment after major surgery is estimated to be 10% in patients over 60 years and this increases with age (Fines & Severn, 2006). One study examined differences in cognitive function in elderly patients who underwent relatively minor surgery as either an inpatient or outpatient (Canet et al., 2003). Higher rates of cognitive impairment were observed at 1 week and at 3 months following surgery in those who were hospitalised for one night compared with those who had surgery as an outpatient. Even hospitalisations that were brief and had less serious surgical procedures had an almost threefold increased risk for development of cognitive impairment at 3 months. Factors related to surgery which could affect changes in cognition include the use of anaesthetic and pain medication, immobilization, physical and psychological stress (Mathews et al., 2013; Terrando et al., 2011), bodily trauma residual effects of complications during surgery and postoperative pain (Woods et al.,

2011). Postoperative delirium has also been found to be a consequence of anaesthesia and surgery and could be predicted by preoperative screening (Fines & Severn, 2006).

The administration of anaesthesia during hospitalisation could also increase the risk of cognitive impairment. However, moderate to major surgery is not performed without anaesthesia, and anaesthesia is not administered unless there is need for surgery. This means we cannot separate the effects of surgery from those of anaesthesia on the risk of cognitive impairment (Docherty & Shenkin, 2016; Silbert, Evered, & Scott, 2011). One study suggests that certain anaesthetics are more harmful than others in regard to resulting cognition (Lewis et al., 2007). Another study found that the accelerated effects of anaesthesia on cognition were only significant in individuals already diagnosed with cognitive impairment (Patel, Lunn, Smith, Lehmann, & Dorrington, 2016). There is only a small amount of literature examining the association between anaesthesia and cognitive impairment. Most studies have used retrospective analysis, have not been able to control for delirium and have found mixed results so we cannot be certain if anaesthesia is a risk factor for cognitive impairment in the long term (Docherty & Shenkin, 2016; Evered, 2017). Patients who received a controlled dose of an anaesthetic to cause a temporary coma or deep state of unconscious, referred to as a medically induced coma, do not undergo surgery. Future studies could examine cognitive impairment in these patients.

During hospitalisation older patients may receive medications that affect their cognition or memory (Chodosh et al., 2004b; Lindquist et al., 2011). Research has found that the use of sedatives or analgesics (Hopkins & Jackson, 2006; Woods et al., 2011), narcotics and other psychoactive medications could be neurotoxic, may alter arousal and increase the risk of cognitive impairment (Mathews et al., 2013). If patients already have some cognitive impairment then the avoidance of certain medications, such as anticholinergics, is needed to avoid any further impairment (Boustani et al., 2010).

There is evidence that comorbid medical conditions, and their severity, are associated with cognitive impairment (Dzierzewski et al., 2014; Mathews et al., 2013). Studies have shown that critical care patients who had hyperglycemia, hypotension, hypoxia (Hopkins & Jackson, 2006) or acute respiratory distress syndrome (ARDS) during their hospitalisation had an increased risk of cognitive impairment (Mathews et al., 2013). Another study found that individuals who were sicker and had longer hospital stays experienced more rapid decline after hospitalisation (Wilson et al., 2012), suggesting that the severity of the medical illness may have contributed to accelerated declines in cognition. However, other studies have found that medical comorbidities are not associated with cognitive impairment (Freedberg et al., 2008). For example, Davydow et al. (2013) found that patients without any comorbid conditions were still at risk of moderate to severe cognitive impairment during hospitalisation.

The patient may also have underlying conditions which led to their hospitalisation or increased the risk of hospitalisation (Chodosh et al., 2004b). These conditions may also be associated with a risk of developing cognitive impairment (Phelan et al., 2012). Such conditions include history of cancer, neurodegenerative diseases (Terrando et al., 2011), cerebral vascular accident (Monk et al., 2008), cardiovascular failure and stroke (Mathews et al., 2013), diabetes, chronic obstructive pulmonary disease and general indicators of physical health like frailty and body mass index (Wilson et al., 2012). For example, in one study patients who had poor physical or instrumental functioning, intertrochanteric fractures or higher medical impairment before surgery were more likely to have cognitive impairment and for the impairment to persist for 2 months (Gruber-Baldini et al., 2003). These conditions could promote neurodegeneration or damage the brain resulting in cognitive impairment (Mathews et al., 2013). Patients with these conditions, particularly those who already have some cognitive impairment, may have trouble self-managing these conditions, creating treatment challenges (Phelan et al., 2012).

Patients with comorbid depressive symptoms are also more likely to develop cognitive impairment (Gruber‐Baldini et al., 2003; Mathews et al., 2013). Older individuals who are hospitalised have increased rates of depression which places them at an increased risk of consequent dementia (Lindquist et al., 2011). One study by Han, McCusker, Cole, Abrahamowicz, and Capek (2008) found that the diagnosis of minor or major depression at hospital administration was associated with subsequent cognitive impairment 1 year after hospitalisation, independent of baseline cognitive function and other comorbidities.

The nature and direction of the relationship between cognitive impairment and hospitalisation is not fully understood. There are many theories about why people with cognitive impairment, especially dementia, have more frequent hospitalisations. One explanation is that dementia increases central nervous system vulnerability to the metabolic effects of acute illness, such that people with dementia are in fact sicker (Phelan et al., 2012). In Mecocci et al. (2005) patients with cognitive impairment were significantly associated with increased risk of geriatric syndromes during hospitalisation. This demonstrates that cognitive impairment is a condition with represents increased frailty in a stressful environment. Furthermore, patients in early stages of cognitive impairment may be at more risk for the medical illnesses that result in hospitalisation or their cognitive impairment leads them to mismanage their medical illnesses to a severe extent (Mathews et al., 2013).

It is hypothesised that patients who have some cognitive impairment after hospitalisation already had some cognitive impairment before admission (Helvik et al., 2012). This impairment may be so mild that it is not detected by screening instruments or has not been diagnosed (Chodosh et al., 2004b; Ehlenbach et al., 2010). In Wilson et al.'s (2012) study they found that older patients and prehospital rates of cognitive impairment were associated with post-hospital cognition. Individuals who had an elevated risk of cognitive impairment, or were already experiencing it, had a greater post-hospital increase in cognitive impairment. This suggests that hospitalisation may reveal

cognitive symptoms in older people or perhaps be associated with declining cognitive performance. Patients in the early stages of cognitive impairment may be at considerable risk of acute mental status changes, injuries, falls or poor self-care arising from their impairment and this may result in hospitalisation (Chodosh et al., 2004b). Although pre-hospital cognitive dysfunction may affect cognition after hospital discharge, the relationship between cognitive impairment and hospitalisation is not primarily due to cognition prior to admission. A number of other factors interact to result in this outcome (Ehlenbach et al., 2010; Mathews et al., 2013).

There are other factors underlying the association between hospitalisation and declines in cognition. Some significant predictors of cognitive impairment include level of education, age, gender and cognitive decline at discharge. Some research has identified that being older, male and having less education is associated with a greater risk of cognitive impairment (Gruber‑Baldini et al., 2003; Monk et al., 2008; Newman et al., 2001). Chen et al. (2011) found that better educated people were more likely to experience dramatic changes in cognition and that more education did not ensure recovery of cognition. Declines in cognition at discharge has been associated with cognitive dysfunction at 3 months (Monk et al., 2008) to up to five years (Newman et al., 2001). Other factors that may predict cognitive changes during hospital stay include persistent and postoperative pain and functional and nutritional status, for example dehydration (Chen et al., 2011; Woods et al., 2011). Mathews et al. (2013) suggest that an individual's resilience may decrease their risk of cognitive impairment after hospitalisation. Factors related to resilience include sufficient treatment of medical conditions, no history of substance use, healthy diet, regular exercise, cognitively stimulating leisure activities and regular social engagement. The relationship between hospitalisation and cognitive impairment is complex and probably predicted by a number of these factors (Dasgupta, 2016).

2.7 Predictors of Health Service Use

2.7.1 The Andersen-Newman Model

To understand the mechanisms underlying healthcare service use in people with cognitive

impairment compared to those who are cognitively healthy it is important to examine whether other

factors are influencing healthcare service use. The Andersen-Newman model is a behavioural model

which details the factors that lead an individual to the use of health services (Andersen & Newman,

1973). In this model the three components that can predict service use are predisposing, enabling

and need variables (Álvarez-Fernandez et al., 2008). Predisposing factors refer to individual

characteristics which may result in more use of health services, even though the characteristics may

not be directly responsible for health service use. Enabling factors are those that enable or impede

individuals to access services. Need factors reflect the severity of the individual's illness (Andersen &

Newman, 1973). Each of these factors, and their contribution to health service use, is discussed in

detail below.

The predisposing factors of the Andersen-Newman model predict that some individuals will be

more inclined to use health services than others (Wolinsky & Johnson, 1991). Predisposing factors

are characterised into three dimensions- demographics, socioeconomic status and health beliefs.

Demographics are generally measured by age, sex, marital status and family size. Socioeconomic

status is measured by employment status, education and ethnicity. Finally, health beliefs measure

attitudes toward disease, using medical services or seeking help (Chipperfield, Campbell, & McKeen,

2004; Lai & Kalyniak, 2005).

The enabling component of the model holds that although an individual may be predisposed to

use services, they must also have the means to obtain them. Enabling factors are divided into two

sub-components. The first sub-component is family resources, usually measured by income, health

insurance coverage and knowledge of services. The second sub-component, community resources, is

measured by physician-and hospital- bed-to-population ratios, proximity to services and population density (Lai & Kalyniak, 2005).

The predisposing and enabling components contribute to the use of health services, however, the individual also must have or perceive some physical or mental illness, or its possibility, for the use of health services to occur. The need to use health services is divided into two indicators, objective and subjective. Objective indicators reflect the physiological dimension of health status, for example test results and diagnosed diseases. They are more accurate measures of the 'need' for health care as evaluated by a professional (Wolinsky & Arnold, 1988; Wolinsky & Johnson, 1991). Subjective indicators reflect the amount of illness the individual perceives exists or the response to his or her physical symptoms. Subjective indicators are accurate measures of the 'demand' on the health services and are generally measured by a self-reported, global measure of health status (Wolinsky & Arnold, 1988). According to the Andersen-Newman model those with more health and psychosocial problems will have higher health care use (Lai & Kalyniak, 2005). Research on health service utilisation in older populations suggests that need factors, including poorer physical and mental health, are the most powerful predictors of service use than predisposing or enabling characteristics (Broe et al., 2002; Chipperfield & Greenslade, 1999; Korten et al., 1998; Parslow, Jorm, Christensen, Jacomb, & Rodgers, 2004).

There has been very little Australian research on the predictors of health service use in patients with cognitive impairment. One US study found that living with a support person increased MCI participants' rate of hospitalisation by 39%. This finding may indicate that older adults with MCI who live alone may delay hospitalisation or not notice warning signs of illness (Callahan et al., 2015). However, another US study by Ennis et al. (2014) found that in both dementia and non-dementia participants living alone was not associated with risk of hospitalisation. Research by Toseland, McCallion, Gerber, and Banks (2002) found that in patients with Alzheimer's or their carers enabling variables explained more variance in service use than need or predisposing variables. A study based

in Taiwan found that the increased use of informal support (i.e. help from their social network) was associated with declines in cognition but that formal service use was not, suggesting that the association between use of formal health care services and cognitive status may differ depending on cultural norms and values (Zimmer et al., 2001).

Fortinsky (2001) expanded the Andersen-Newman model to address the use of health care by people with cognitive impairment. This expanded model argues that the level and quality of GP services used by cognitively impaired individuals is affected by the ability of GP practices to recognise symptoms in older patients, manage these symptoms and help find support services for both patients and their families (Fowler et al., 2012).

The factors that may predict the use of health services (GP, hospital and emergency department) found in previous research are discussed in more detail in Chapter 7. Chapter 7 also includes a paper about the service use of individuals across the spectrum of dementia.

2.8 Summary

This chapter has provided a brief overview of the literature about the disorders, theories and issues discussed within this thesis. It began by providing a definition of the process of knowledge translation, it then followed with an outline of MCI and its position in the spectrum of dementia. The chapter then reviewed the research on three different types of health care services- general practitioner, emergency department and hospital- and how they may affect, or be affected by, cognitive impairment. This chapter then concluded with an explanation of the Andersen-Newman model, which is used in this thesis to explain predictors of health service use.

2.8.1 Gaps in the Literature

From the literature review a number of research gaps have been identified. Firstly, the limited literature examining the relationship between GP use, hospital use and cognitive impairment has

predominately been based on non-Australian populations. There are only a few studies with long-term follow-up periods based in Australia which examine the association between GP, hospital use and cognitive impairment. To determine the level of need for healthcare service use in the Australian population with cognitive impairment, which may have important implications for our policies and programs, more research is required. This thesis will examine the association between GP use, hospital use and cognitive impairment in the Australian context, specifically the ACT.

Secondly, to the author's knowledge, there has been no previous research on the determinants of healthcare service use by people with MCI. Given this lack of research this thesis will analyse the predictors, or determinants, of healthcare service use in people with cognitive impairment. By examining what drives specific populations to access services we can construct programs and services and then evaluate how appropriate they are.

Thirdly, although there is an understanding of the need for evidence based policy and the process of knowledge translation, there have been limited documented strategies to effectively translate research into health policy. One of the aims of this thesis (described in Chapter 1) is to discuss knowledge translation and provide ways of optimising research so that it can be effectively translated into policy. This thesis will also discuss the policy implications from the research presented.

The literature review has described the previous research findings on healthcare service use and cognitive impairment, our own study findings will be discussed in part three of this thesis. After providing our own findings we will discuss how these research findings may be important to current policies, programs or practice and the most efficient way to communicate these findings to policy makers.

Chapter 3: MATERIALS AND METHODS

3.1 Introduction

This thesis uses secondary data from a cross-sectional web-based survey, two qualitative interviews and three longitudinal datasets. In this chapter I begin by briefly discussing the Australian Research Council (ARC) Linkage Grant on Knowledge Translation in Population Health and Dementia, the web-based survey and two qualitative interviews which were projects in the ARC Linkage grant. I then describe the three longitudinal datasets in detail, including participant recruitment, ethics procedures, the variables measured, data management and statistical analysis. This chapter concludes with a discussion on the ethics of data linkage.

The first dataset used in this thesis contains data collected from the Personality and Total Health (PATH) Through life study, including a sub-study called the Health and Memory study. The second dataset is the Australian Capital Territory (ACT) Admitted Patient Care (APC) data and the third is the ACT Emergency Department Information System (EDIS). The second and third datasets were linked to the PATH dataset using the Master Linkage Key services provided by the Centre for Health Record Linkage (CHeReL). Studies within this thesis use either the PATH dataset, the ACT APC data, or all three datasets.

3.2 Australian Research Council Linkage Grant

An Australian Research Council (ARC) Linkage Grant on Knowledge Translation in Population Health and Dementia was awarded in 2013. The linkage grant involved a partnership between the Centre for Research on Ageing, Health and Wellbeing (CRAHW) and ACT Health Directorate. The aim of the grant was to develop better ways of ensuring that the highest quality evidence from observational research is used by decision-makers in population health. The grant involved three different projects. The first project was to develop a grading system for evidence derived from

observational studies. This project involved conducting in-depth interviews with experts in chronic disease epidemiology to identify their views on the characteristics of high quality observational research and their use of currently available rating systems.

The second project was to understand how policy makers identify, access, select and use evidence in population health. This project involved semi-structured interviews with policy makers, policy advocates and program managers about how they source and use evidence from observational studies to make decisions relating to public health. To supplement the knowledge gained from the in-depth interviews, a web-based survey was conducted. The web based survey and interviews from Project one and Project two are described in more detail below.

The third project on the grant was focused on developing a model for research training that 'enables' research to be conducted in a manner that facilitates or optimises knowledge translation. The funding and completion of this PhD thesis was one of the outcomes of that project. To fulfil the outcomes of the grant the research plan for this PhD was developed collaboratively by the ACT Health Directorate and the PATH investigators. The PhD was to analyse the PATH dataset (details below), with research questions that address scientific questions and provide outcomes that directly inform ACT Health Directorate's policy. It was expected that the project would focus on linking cognitive health with service use longitudinally. As part of this project the author was to spend a three-month period based at ACT Health Directorate as part of a "Research Translation Internship".

3.3 Web-Based Survey and Qualitative Interviews

The clinical investigators of the ARC Linkage Grant, in consultation and collaboration with ACT Health and Alzheimer's Australia, designed and conducted a cross-sectional web-based survey. This web-based survey was designed to understand how policy makers identify, evaluate and use

scientific knowledge or 'evidence' when developing policies. Individuals who were involved in the development or evaluation of policy ('policy makers') were invited to participate in the study.

Two semi-structured qualitative interviews were also conducted, one with epidemiologists and one with policy makers. Epidemiologists were asked about what constitutes high quality observational evidence, their view on how evidence is rated, if they were aware of and used rating systems for grading evidence, and the problems associated with rating observational research. Policy makers were asked about their preferred source of evidence, what they consider to be "high quality evidence," barriers to accessing research and ways of increasing the use of research in policy making (e.g. increased access to research or data, the usefulness of current research, policy makers being more receptive of research etc.)

The study design of the web-based survey and two qualitative interviews are described in detail in the article in Chapter 4 (paper 1). The web-based survey and interview questions are provided in Appendix A.

3.4 The Personality and Total Health (PATH) Through Life study

The PATH study is conducted by principal investigators at CRAHW at the Australian National University (ANU). The study has three broad aims: 1) to delineate the course of depression, anxiety, substance use and cognitive ability across the adult life span; 2) to identify environmental and genetic risk factors and protective factors influencing individual differences in the course of these characteristics; and 3) to investigate inter-relationships over time between the three domains of depression and anxiety, substance use, and cognitive ability and dementia. These aims relate to clinical outcomes that constitute the major burden of disease within the Australian community. (Anstey et al., 2012)

3.4.1 Recruitment of Participants

The PATH study uses a cohort-sequential design. At baseline these cohorts were aged 20-24 years (20+), 40-44 years (40+) and 60-64 years (60+). By the end of 2015, four waves of data had been collected for all three cohorts with 4-year intervals between interviews. Each cohort was interviewed over a period of 1 year starting with the 20+ cohort in 1999 and the third and final cohort, aged 60-64, surveyed for the first time in 2001. The sample are community-dwelling individuals drawn from the electoral rolls of the three federal electorates that make up the Australian Capital Territory and the electorate that contains the neighbouring town of Queanbeyan, New South Wales.

The analyses in this thesis focuses on the 60+ age group, who were interviewed in 2001-2002, 2005-2006, 2009-2010, 2013-2015. At baseline 2,551 people over 60 completed the interview. At wave two, 2,222 participants completed the PATH interview (12.9% attrition). At wave three, 1,973 participants were interviewed (11.2% attrition) and at wave four, 1,645 participants were interviewed (16.6% attrition).

All PATH participants were asked if they consented to their records being linked with the Medicare Benefits Schedule (MBS) and other external datasets. The MBS is a list of Medicare services subsidised by the Australian government. It includes the date of consultation and the type of service provided. Data for each individual was collected for the period 6 months prior to and 6 months after the PATH interview was collected.

In addition to the main study, three more studies were undertaken drawing on subsamples of PATH. One of these studies is the "Health and memory sub-study." In each wave, participants in the 60+ cohort who performed poorly on selected cognitive tests were asked to complete a detailed neurocognitive assessment. Some of these participants also underwent an MRI scan and blood test. Participants were selected for clinical assessment if they had any of the following: (i) a Mini-Mental State Examination (MMSE) (Folstein, Robins, & Helzer, 1983) score $\leq$ 25, (ii) a score from wave one

below the fifth percentile of the California Verbal Learning Test (Delis, Kramer, Kaplan, & Ober, 1987) on immediate or delayed recall (immediate or delayed score of <4 and <2, respectively), or (iii) a score below the fifth percentile on two or more of the following tests: Symbol Digit Modalities Test (Smith, 1982) (<33) or Purdue Pegboard with both hands (Tiffin, 1968) (wave 1, <8; wave 2, <7), or simple reaction time (third set of 20 trials; wave 1, >310 ms; wave 2, >378 ms) (Anstey, Dear, Christensen, & Jorm, 2005).

To achieve a diagnosis, selected participants underwent a semi-structured neurological and clinical interview, additional neuropsychological assessment and a structured checklist which outlined criteria for multiple criteria for diagnosis. The clinical interview included the following: medical history, physical examination, neuropsychological testing (frontal executive functioning, memory, language, visuoconstructive, praxis, Gnosis and calculation), handedness, clinical dementia rating, alcohol, functional assessment and depression rating. Following the interview, permission was obtained to interview an informant and to contact the participant's GP if required. Diagnoses were formulated from clinical checklists, data from the neuropsychological assessment, and neuropsychological and medical history (Anstey et al., 2012). A case summary was configured and a preliminary diagnosis constructed. Consensus diagnosis was achieved by two clinicians- an experienced senior psychiatrist and a medical officer.

3.4.2 Ethics

A Data Sharing Agreement is required for sharing of PATH data and only de-identified data is released. The PATH Governance Committee provides approval to access the PATH dataset. The PATH Governance Committee is composed of the Chief Investigators on the current NHMRC funding grant. PATH and its sub-studies are approved by the ANU Human Research Ethics Committee. The ethics approval for PATH at Wave 1 #M9807 was approved on 1st September 1998, Wave 2 #2002/189 on 11th November 2002, Wave 3 #2006/314 was approved on 21st December 2006 and Wave 4 #2010/542 on 4th March 2010. The approval for Health and Memory substudy Wave 1 and Wave 2

#2001/2 was approved on 6th March 2001, Wave 3 #2009/039 on 25th March 2009 and wave 4 #2010/542 on 9th April 2013.

3.4.3 Variables

The specific research objectives for each wave of data collection were developed by the chief investigators and form the basis of ongoing research at CRAHW, ANU. Hence every variable and outcome measure in the study has been chosen by a researcher for a specific purpose. The following section details the study measures used in this thesis.

3.4.3.1 Health variables

Self-rated health was assessed using the 12-item Short Form Health Survey (SF-12) which gives two summary measures- physical health and mental health. The SF-12 has recently been validated for use in Australia, with the SF-12 items predicting at least 90% of the variance in both the physical and mental health measures (Sanderson & Andrews, 2002).

The Brief Patient Health Questionnaire (BPHQ) was used to measure symptoms of depression (Spitzer, Kroenke, Williams, & and the Patient Health Questionnaire Primary Care Study, 1999). A study by Kiely and Butterworth (2015) found that a cut-off point of 8 on the BPHQ-9 had a sensitivity of 0.79 and specificity of 0.86. The Goldberg's scale was also used to measure participants' symptoms of anxiety and depression (Goldberg, Bridges, Duncan-Jones, & Grayson, 1988). This scale is an 18-item questionnaire with "Yes/No" responses to questions asking how the participant has been feeling in the past month. Items are scored 0 (no) or 1 (yes) and summed. A cut-point of 5 on the depression scale has a sensitivity of 0.81 and a specificity of 0.83. A cut-point of 7 on the anxiety scale has a sensitivity of 0.84 and specificity of 0.86 (Kiely & Butterworth, 2015).

Participants self-reported if they had been diagnosed with any of the following conditions: arthritis, high blood pressure, cancer, stroke, thyroid, diabetes, asthma bronchitis or emphysema, cataracts or heart problems.

3.4.3.2 Psychosocial variables

Participants' level of education was measured by asking participants their highest level of schooling completed and then the level of post-secondary or tertiary education completed. The level of school completed was then used to calculate the total years of education completed.

Each participant's social network was measured using the 6-item Lubben social network scale (Lubben, 1988). This scale has an internal reliability of 0.83. In accordance with previous research (Lubben et al., 2006) a cut-point of 12 was used to categorise participants into 'at risk of social isolation' or 'not at risk'. The social support scale developed by Schuster, Kessler, and Aseltine (1990) was also used. This scale measures both positive and negative interactions with spouse, family and friends.

To measure financial status participants self-reported if they had experienced any financial problems, if they received a full or part time pension and if the pension was their only income. Levels of role strain, or assumed household responsibility, was measured using three questions. Participants were asked to indicate the extent that they were responsible for financial management, housework and providing money for the household, from "Fully responsible" to "Not at all responsible". The responses were summed to give a total role strain score.

Finally, mastery, or individual's sense of control, was measured using the Pearlin Personal Mastery Scale (1981). This scale consists of 7 statements, positively and negatively worded, which participants respond to on a four-point scale from 1= "Strongly Agree" to   4= "Strongly Disagree". Negatively worded statements were reverse coded and the scores summed. A low score suggests a high level of control and a high score suggests a low level of control. This scale has demonstrated good construct validity and internal reliability (Pearlin, Menaghan, Lieberman, & Mullan, 1981).

3.4.3.3 Behavioural variables

Smoking status was assessed by asking participants if they currently or had previously smoked. Harmful or hazardous alcohol consumption was measured using the Alcohol Use Disorders

Identification Test (Saunders, Aasland, Babor, De La Fuente, & Grant, 1993). Harmful alcohol

consumption was defined as >42 units per week for men, >28 units per week for women. Hazardous

alcohol consumption was defined as 28-42 units per week for men and 14-28 units for women.

Participants who had not drunk alcohol in the last year were classified as 'abstainers.'

Participants were asked about the frequency of physical activity (from "Never" to "3 times a

week or more") and the total number of hours spent exercising per week. Each of these required

separate responses for level of activity- mild, moderate and vigorous. The number of hours of

exercise per week was then summed and dummy coded. None/mild exercise was coded as less than

moderate or vigorous, moderate was equal to or more than 1.5 hours per week of moderate but less

than 1.5 hours of vigorous, or 30 minutes to 1.49 hours per week of both moderate and vigorous per

week, and vigorous activity was equal to or more than 1.5 hours of vigorous activity per week.

3.4.3.4 Cognitive variables

Short-term memory was assessed by immediate and delayed recall of the first trial of the

Californian Verbal Learning Test (CVLT) (Delis et al., 1987). This test involves participants recalling a

list of 16 nouns. Digit span backwards is a subtest from the Wechsler Memory Scale (Wechsler,

1981) and tests working memory. Numbers were read out to participants at one second intervals.

When the participant incorrectly repeated numbers on two trials no further trials were given. The

Symbol Digit Modalities Test (SDMT) (Smith, 1982) requires individuals to identify the corresponding

symbol to the digits 1-9 based on a key. Participants were given 90 seconds to complete as many

symbol-digit pairs as possible. The SDMT assesses participant's processing speed. Verbal ability was

measure with the Spot-the-Word test which was self-completed by the participant on a computer

screen. In this task participants choose the real words from 60 pairs of words and non-words

(Baddeley, Emslie, & Nimmo Smith, 1992). Finally, the Mini Mental State Examination (MMSE)

(Folstein et al., 1983) was administered to participants. The MMSE was developed to screen for

dementia and cognitive impairment. The MMSE is an 11-item questionnaire that tests five areas of

cognitive function: orientation to time and place, short-term memory, calculation, immediate recall, constructive ability and language. The maximum score is 30 and a score of 23 or lower is indicative of severe cognitive impairment. This cut-point has a sensitivity of 0.66, specificity of 0.99 and overall correct classification rate of 88.9% (O'Bryant et al., 2008). For the Health and memory sub-study, individuals who scored 25 or below on the MMSE were screen positive for cognitive impairment.

3.4.4 Data Management

All PATH data and supporting documentation, including a description of the project, syntax files and variable lists, are stored in a shared network drive on the ANU network which requires permission to be accessed. Computers to access this drive were password protected. The PATH data is saved in an SPSS file and all statistical analyses were performed using statistical software SPSS. The details of statistical analyses are discussed in detail in the relevant chapters (Chapter 5, 6 and 7).

3.5 ACT Admitted Patient Care and ACT Emergency Department Information System

This section discusses how data on consenting PATH participants' hospital and emergency department use was extracted from the ACT Admitted Patient Care (APC) data and the ACT Emergency Department Information System (EDIS). The ACT APC data records all inpatient separations (discharges, transfers and deaths) from all public and private hospitals in ACT. The ACT EDIS provides information about patient presentations to the emergency departments of public hospitals in the ACT. Currently, only data from Canberra Hospital is included in the Master Linkage Key (MLK).

The MLK is a system of continuously updated links within and between core-health related datasets, such as the Cancer Registry or mortality data, in NSW and the ACT. The MLK is constructed by the Centre for Health Record Linkage (CHeReL). APC and EDIS records were extracted from the

MLK (Version 2014_03) for the periods and participants of interest (Table 1). The MLK consists of identifying information such as name, address, date of birth and gender which are used to match records. The MLK does not contain health or content data.

3.6 Data Linkage Process

The PATH data was provided to CHeReL with the following identifiers for linkage: Given name, Middle name, Family name (surname), Date of birth, Sex, Address. Locality/Suburb, State and Post code. The PATH data custodian also provided a record identification number (RecID), a unique code number which is assigned to each PATH participant and provided to CHeReL in order to maintain privacy. The RecID is different from the participants original PATH ID.

The MLK extract was linked to the PATH records using probabilistic record linkage methods and *ChoiceMaker* software (Borthwick, Buechi, & Goldberg, 2003). Probabilistic matching computes weights for identifiers based on how well they can identify a match or a non-match, and uses these to calculate a probability that two records match. From this record pairs are classified as matches, non-matches or possible matches.

ChoiceMaker uses 'blocking' and 'scoring' to identify definite and possible matches. During blocking, *ChoiceMaker* searches the target datasets for records which are possible matches to each other. There are two types of blocking. The exact blocking algorithm requires records to have the same set of valid fields and the same values for these fields. The automated blocking algorithm builds a set of conditions that are used to find as many records as possible that potentially match each other. Scoring employs a combination of a probabilistic decision, which is computed using a machine learning technique, and absolute rules which include upper and lower probability cut-offs, to determine whether each potential match denotes or possibly denotes the same person. Upper and lower probability cut-offs initially start at 0.75 and 0.25 for a linkage and are adjusted for each individual linkage to ensure false links are kept to a minimum. The false positive rate for this extraction was 3/1,000 records (0.3%).

Once the linkages were finalised, CHeReL created a Project Person Number (PPN) for each person identified in the linkage and assigned this PPN to the PATH, APC, and EDIS records. CHeReL returned the PPN and the matching RecID from the PATH dataset to the data custodians. The data custodians are staff from ACT Health Government Epidemiology Branch. The data custodians then supplied the datasets with all the approved information from the source database plus the PPN to the project investigator (the author).

To allow linked records for the same individual to be identified and extracted the project investigator had to match the PPN generated by CHeReL to the unique RecID which the PATH data custodian has assigned to each PATH participant. The RecID was then matched to each participant's original PATH ID number. The results of the linkage are given in Table 2.

3.6.2 Ethics

To gain approval to access CHeReL data an appropriate legal basis and ethics approval was required. Firstly, the project investigator was required to complete the CHeReL Application for Data form. This form outlines the project, including details of the investigators, the background, aim, research design and methods of the study, datasets to be linked and the linkage required. Investigators must also specify participant consent and the storage and retention of data. The investigators also specified those variables from both APC and ED data they wanted (e.g. date and time of admission, date and time of separation) and provided a research protocol. After reviewing these documents CHeReL provided the project investigators with a technical feasibility letter.

Ethics approval was then sought from the ACT Health Human Research Ethics Committee for the project. Approval from the PATH and ACT Health data custodians was also requested. Once these were approved the PATH data custodian provided CHeReL with personal identifiers from the PATH dataset. No clinical data were sent to CHeReL. PATH data were encrypted with a password and transferred to CHeReL using a secure file transfer facility.

3.6.3 Variables Requested

The variables requested for ACT APC data include age in years at time of admission, sex and marital status of participant, the date and time of admission, the date and time of separation and the length of stay. Day stay flags indicating if the patient's admission was a same day or overnight stay were also requested. To identify the amount of time each PATH participant spent in hospital between waves each episode of hospital care was linked and the length of stay summed to form a complete hospital stay variable. Primary and additional diagnosis, up to 100 diagnoses, was requested, along with Major Diagnosis Category, to check if hospital admission was related to, or contributed to, declines in cognition. Finally, the hospital service-care type and separation mode were requested.

The variables requested for ACT EDIS included age, sex and marital status. A number of time variables were requested, including arrival date and time, triage date and time, seen date and time and actual departure date. To gauge the seriousness of the condition triage category, type of visit, diagnosis and departure status were requested. The triage category is a number between one and five which indicates how quickly patients should be treated based on how critical their condition is, with category one patients requiring immediate resuscitation. The type of visit describes whether the presentation is an emergency visit, return visit, if it is pre-arranged, if the patient is in transit or if the patient is dead on arrival. Finally, the departure status indicated whether the patient was admitted to the hospital, if they were referred to another hospital, if they departed without being admitted or referred to another hospital, if they did not wait to be attended by a health professional or left at their own risk after being attended by health professional but before the emergency department service episode was completed. If they died in the emergency department as a non-admitted patient or were dead on arrival.

3.6.4 Data Management

The ACT APC and ACT EDIS datasets were stored on password protected files on password protected computers. These datasets were saved in both Microsoft Excel and SPSS formats. All statistical analyses were conducted using SPSS. Details on statistical analysis, including exclusion criteria and missing data, are provided in the manuscripts in Chapters 6 and 7.

3.7 Value and Ethical Implications of Data Linkage

Data linkage is crucial to the ongoing improvement of health and health care across Australia. Health-related data linkage systems can facilitate the provision of information for planning, monitoring and evaluating health services and programs. There are many benefits associated with the use of linked data in research. Firstly, by linking two datasets together researchers can conduct detailed research on whole populations, thus generating a more complete picture of the health of those in the community. Secondly, it adds value as researchers are provided with information not routinely included in their own study (Sibthorpe et al., 1995). Thirdly, these datasets are collected over a long period of time and so allow for longitudinal analysis. As these datasets already exist and provide information on whole populations, data linkage is also cost effective, meaning that funds available to carry out health and medical research are used more effectively and for greater public benefit (Bass et al., 2008; Boyd et al., 2015). Data linkage also offers timely information which provides researchers and clinicians the opportunity to react quickly to adverse health trends, detect health service problems and improve clinical practice. Finally, data linkage allows for a number of research questions and designs to be used, for example evaluating cost, comparing groups and having long-term follow-up of research (Jorm, 2015). Given all these benefits data linkage has huge potential to address policy-related issues.

Although data linkage is a valuable tool there are a number of ethical risks associated with it. Most of these risks are to participants. These include psychological harms, devaluation of personal

worth, social harms, economic harms and legal harms. In order to minimise the risks to participants data linkage uses the separation principle (PHRN, 2011). This allows research to be done in a way that protects individual's privacy and confidentiality. This happens in two ways. Firstly, risk is minimised through the physical separation of personal data from content data. The only person in the linkage process who has access to both personal and content information is the data custodian. Data linkers are not given content information, and researchers are not given personal information. Neither researchers nor data linkers are able to connect a person with clinical or health-related information. This may occur in a small population like Canberra or rural sites, however, the separation principle tries to minimise this risk. The second way risks to participants are minimised is through the separation of functions and responsibilities in the data linkage process. To decrease risks data linkers can only link personal information. They should not be involved in the analysis of the linked content data or be able to discuss the data with the researcher. The data linker or research cannot also be a data custodian. The data linkage process must be entirely separate from the data custodianship and extraction of data.

In summary, in order to minimise risks to participants (and as an ethical consideration) data linkers should only have access to personal data. Researchers should only have access to content, or health, data. Data custodians are the only individuals who will have access to both personal and content data. An individual cannot have multiple roles in the data linkage process. A data custodian cannot undertake research or do linkage using the data that they have access to, and a researcher cannot be a data custodian or a data linker. These standards are to minimise risks to participants, and is the principle that data linkage centres use.

3.8 Summary

This chapter has discussed the materials and methods employed throughout this thesis. This chapter has provided a detailed description of the three secondary datasets- the PATH, ACT APC,

and ACT EDIS- and the process of linking these datasets together. This chapter also discussed the

value and ethical implications of linking datasets together. The two qualitative studies and web-

based survey briefly described at the beginning of this chapter are discussed in the manuscript in the

next chapter.

Table 1: Data sources and record types

Data Source	Description	Number
Personality and Total Health (PATH) Through Life	PATH Study participants: Persons aged 40 and over who reside in the ACT and surrounding areas.	4,660 records
ACT Admitted Patient Care (ACT APC)	Canberra Hospital admissions: Separation Date: 1 Jul 2004 – 30 Jun 2013	598,322 records
ACT Emergency Department Information System (ACT EDIS)	Canberra Emergency Department Admission dates: 1 Jul 2005 – 30 Jun 2013	458,515 records

Table 1: Data sources and record types

Table 2: Summary of records returned to Study investigators

Data Source	Record type	Number
PATH	All records	4,660 records (4,660 persons)
	PATH records that linked to ACT APC	1,157 records (1,157 persons)
	PATH records that linked to ACT EDIS	1,332 records (1,332 persons)
	Total linked PATH records	1,658 records (1,658 persons)
ACT APC	APDC records that linked to the above PATH records: Separation date: 1 Jul 2004 – 30 Jun 2013	4,907 records (1,157 persons) 24.83% of cohort
ACT EDIS	EDDC records that linked to the above PATH records: Admission date: 1 Jul 2005 – 30 Jun 2013	2,932 records (1,332 persons) 28.58% of cohort
Total Records to be returned to Study Investigators: Total Project Person Numbers (PPN):		9,497 records (1,658 persons)

Table 2: Summary of records returned to Study investigators

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PART 2.

Chapter 4: EVIDENCE BASED POLICY AND KNOWLEDGE TRANSLATION

4.1 Introduction

Part one of this thesis provided an introduction to this study including a literature review of previous research and the materials and methods used in this thesis. Part two will discuss evidenced based policy and the process of disseminating evidence for use in policies, termed knowledge translation. This chapter begins by providing a brief definition of evidenced based policy and then a manuscript which discusses the different types of evidence used by policy makers as compared to academic epidemiologists. It will discuss the process of knowledge translation and provide a brief outline of six different frameworks for knowledge translation (KT). One of these, the WHO "KT framework for Ageing and Health" will be described in depth, applying components of this framework to the author's local context. This chapter will then discuss the most common barriers and enablers of knowledge translation before concluding with a second manuscript on the use of secondments as a tool to increase knowledge translation between researchers and policy makers.

4.2 Evidence Based Policy

Health policies are a good example of interventions that are of low intensity but can have broad reach and impact (Glasgow & Emmons, 2007). People expect their government to mandate an array of public policies and programmes to deal with health challenges (World Health Organization, 2008). The Australian government has stated that, to improve public health outcomes, quality scientific research should be used throughout the development of health policies (Australian Medical Research Advisory Board, 2015; Zardo & Collie, 2014).

The term health policy can be defined as:

"*decisions, plans, and actions that are undertaken to achieve specific health care goals within a society. An explicit health policy can achieve several things: it defines a vision for the future which in turn helps to establish targets and points of reference for the short and medium term. It outlines priorities and the expected roles of different groups; and it builds consensus and informs people*" (World Health Organization, 2017).

Policy cannot be categorised by a single decision point. Instead, it is a series of decisions, all of which contribute to its planning and implementing (Shaxson, 2009). Evidence, both qualitative and quantitative, can impact on health policies at several points in the development process, or policy cycle, from when a problem is identified to the development of the most appropriate response and evaluation of its effectiveness (Moore, Todd, & Redman, 2009; Petticrew, Platt, McCollam, Wilson, & Thomas, 2008). One depiction of the policy cycle (Figure 2) shows five phases in which research can be utilised. These phases may not occur linearly and policy makers may jump back and forth between them. The first phase is anticipation, when policy makers identify an issue and set an agenda. Researchers can introduce new research and ideas to policy makers or raise awareness of problems in this phase. The second phase, formulation, is when available information and evidence on the issue is gathered from a range of services and analysed to inform policy options. This phase provides an opportunity for researchers to provide policy makers with direct access to evidence or help to evaluate research and previous policies. Consultation is the third phase. In this phase policy options are tested through consultation with key stakeholders, including researchers. The fourth phase, adoption, involves decision-making and implementation. This phase provides an opportunity for researchers to provide strong evidence to assist with a decision or inform the process for rolling out a policy. Finally, the fifth phase is evaluation. In this phase the effectiveness and impact of the policy is assessed. Researchers could contribute to the design of an evaluation framework, collect data and conduct final evaluations (Brown, Hagger, & Bywood, 2015).
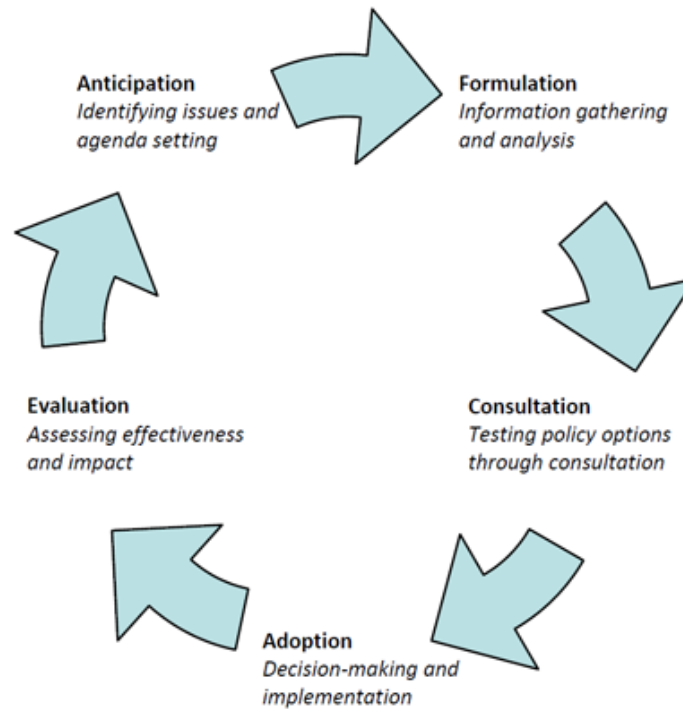
Figure 2. The policy cycle.

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4.3 Paper 1: Evaluating and using observational evidence: the contrasting views of policy makers and epidemiologists

There is considerable variation in what is understood by the term 'evidence based policy.' Broadly defined, evidence based policy making is a process that uses rigorous and tested evidence in the design, implementation and refinement of policy to meet designated policy objectives (Productivity Commission, 2010). Brownson and Jones (2009) argue that to be regarded as evidence based policy, decision makers in public health should make decisions using the best available peer-reviewed evidence (both qualitative and quantitative), systematically use data and information

systems, apply program-planning frameworks, engage the community in assessment, conduct a thorough evaluation and disseminate what is learned to key stakeholders and other decision makers.

In the 'real world' of policy making, policy decisions are informed by several factors, including political views and decisions, perceived public opinion and pragmatic constraints such as funding and cross-jurisdictional agreements. Although the importance of evidence based policy has been recognised in Australia and internationally, it has been identified that policy makers use a broad range of evidence to inform decisions not just academic research (Bowen & Zwi, 2005; Popay, Pope, & Mays, 2006).

Little is known about the types of information that are best for the policy development process or how policy makers evaluate the quality of evidence. Furthermore, policymakers' definition of evidence may not match academic constructions of 'evidence' (Innvaer, Vist, Trommald, & Oxman, 2002; Oliver, Innvar, Lorenc, Woodman, & Thomas, 2014a; Oliver, Lorenc, & Innvær, 2014b; Orton, Lloyd-Williams, Taylor-Robinson, O'Flaherty, & Capewell, 2011). The following article 'Evaluating and using observational evidence: the contrasting views of policy makers and epidemiologists' examines the types of information policy makers mostly use in the decision-making process. The article also examines which type of evidence is considered the best quality.

Statement of authorship

Evaluating and using observational evidence: the contrasting views of policy makers and epidemiologists. *Frontiers in Public Health.* (2016) 4:267. doi: 10.3389/fpubh.2016.00267.

Lily O'Donoughue Jenkins (PhD candidate)

Developed manuscript design; conducted statistical analysis; interpreted data; drafted and edited the manuscript; acted as corresponding author. I certify that the statement of contribution is accurate

Signed…………………………… Date…………………….

Paul Michael Kelly

Assisted in developing the study concept and design; drafted and provided critical revision of the article; assisted in interpretation of data analysis; provided final approval of the manuscript to be published. I certify that this statement of contribution is accurate and permission is given for Lily O'Donoughue Jenkins to include this paper in this thesis for examination towards the Doctor of Philosophy

Signed…………………………… Date…………………….

Nicholas Cherbuin

Assisted in developing the study concept and design; drafted and provided critical revision of the article; assisted in interpretation of data analysis; provided final approval of the manuscript to be published. I certify that this statement of contribution is accurate and permission is given for Lily O'Donoughue Jenkins to include this paper in this thesis for examination towards the Doctor of Philosophy

Signed…………………………… Date…………………….

Kaarin Anstey (Principal Supervisor)

Developed the study concept and design; funded the information technology for the study; oversaw data collection; drafted and provided critical revision of the article; assisted in interpretation of data analysis; provided final approval of the manuscript to be published. I certify that this statement of contribution is accurate and permission is given for Lily O'Donoughue Jenkins to include this paper in this thesis for examination towards the Doctor of Philosophy

Signed…………………………… Date…………………….

Evaluating and Using Observational Evidence: The Contrasting Views of Policy Makers and Epidemiologists

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Background: Currently, little is known about the types of evidence used by policy makers. This study aimed to investigate how policy makers in the health domain use and evaluate evidence and how this differs from academic epidemiologists. By having a better understanding of how policy makers select, evaluate, and use evidence, academics can tailor the way in which that evidence is produced, potentially leading to more effective knowledge translation.

Methods: An exploratory mixed-methods study design was used. Quantitative measures were collected via an anonymous online survey ($n = 28$), with sampling from three health-related government and non-government organizations. Semi-structured interviews with policy makers ($n = 20$) and epidemiologists ($n = 6$) were conducted to gather qualitative data.

Results: Policy makers indicated systematic reviews were the preferred research resource (19%), followed closely by qualitative research (16%). Neither policy makers nor epidemiologists used grading instruments to evaluate evidence. In the web survey, policy makers reported that consistency and strength of evidence (93%), the quality of data (93%), bias in the evidence (79%), and recency of evidence (79%) were the most important factors taken into consideration when evaluating the available evidence. The same results were found in the qualitative interviews. Epidemiologists focused on the methodology used in the study. The most cited barriers to using robust evidence, according to policy makers, were political considerations (60%), time limitations (55%), funding (50%), and research not being applicable to current policies (50%).

Conclusion: The policy maker's investigation did not report a systematic approach to evaluating evidence. Although there was some overlap between what policy makers and epidemiologists identified as high-quality evidence, there was also some important differences. This suggests that the best scientific evidence may not routinely be used in the development of policy. In essence, the policy-making process relied on other jurisdictions' policies and the opinions of internal staff members as primary evidence sources to inform policy decisions. Findings of this study suggest that efforts should be directed toward making scientific information more systematically available to policy makers.

Keywords: policy making, knowledge translation, evidence-based practice, government, mixed-methods research

Abbreviations: ACT, Australian Capital Territory; EBM, evidence-based medicine; HREC, Human Research Ethics Committee; KT, knowledge translation; RCT, randomized controlled trial; NGO, non-government organization.

INTRODUCTION

There has been increasing discussion that in order to improve public health outcomes quality scientific research should be used throughout the development of health policies (1). The process of disseminating academic research to policy makers is referred to as knowledge translation (KT) or knowledge exchange (2). The process of KT involves many activities and specific practices, including producing synthesized research aimed at informing policy, writing plain language summaries of findings, and spending time with users to understand their context and research needs (3). It is believed that if KT is done effectively then the use of scientific evidence in policy and practice decisions will be increased (4).

In the "real world" of policy making, scientific research is just one of many types of information used (5). Policy makers interpret and "use" evidence in a broad sense (e.g., non-research data such as public health surveillance data and strategic needs assessments) (6). There is also a range of political, economic, and social drivers which affect decisions during policy development. In order to support a particular policy agenda, while also managing the competing interests of diverse stakeholders, policy makers may use specific information without giving consideration to all the available evidence (4, 7) or may not be able to directly translate the findings, or recommendations, from epidemiological research into action within their particular context (8).

Previous research has focused on the apparently low uptake of academic research by policy makers, with particular attention given to understanding how and under what circumstances policy makers access and use academic evidence (9). However, the needs and practices of policy makers are rarely the subject of rigorous study and are likely to be more complex and nuanced than can be captured in surveys (6). For example, three systematic reviews (10–12) discussed the facilitators and barriers to the use of evidence in policy making and identified that policy makers use a broad range of evidence. These studies could not find reliable evidence of how much policy makers use academic research in the policy making process or how the definition of evidence by policy makers differs from the conceptualization of what is classified as evidence by researchers. As such, we require a clearer understanding of how policy makers define and use evidence (13).

Currently, little is known about what types of information and evidence is normally used as part of the policy development process or the extent to which political agendas and budgetary constraints influence the design and choice of policy options (6, 9, 14). In one of the few studies investigating the sources of research evidence that policy makers in government accessed when making a decision, academic literature was one of the least frequently used sources, along with internal expertise, policy documents, and employing a consultant (15). A study by Head et al. (9) found that the most valued source was the knowledge of their immediate colleagues (93%). Their study also found that over 40% of policy makers reported that academic research was used in informing policy and legitimizing policy choices. However, the majority also stated that policy making was overwhelmingly driven by budgetary considerations (83%), political acceptability

of decision (80%) and responding to urgent day-to-day issues rather than "long-term" thinking (75%) (9).

By investigating the type of research that policy makers use to inform policy decisions, how they identify evidence and what other factors may influence policy decisions, we can identify what information is viewed as more relevant and timely (6). This may contribute to researchers better tailoring their research to policy maker's needs and thus improving KT processes and the take up of scientific evidence in the policy development process.

There is also a need to investigate how policy makers select and evaluate the quality of evidence. One way of selecting and evaluating evidence is by using an "evidence hierarchy." This hierarchy may consider certain types of experimental research, for example randomized controlled trials (RCTs) and systematic reviews of RCTs, as highest in methodological quality (16). Researchers and clinicians use particular grading instruments to grade the quality of evidence. An example of such an instrument is Grading of Recommendations, Assessment, Development and Evaluation, which evaluates biomedical evidence based on risk, burden, and cost of intervention (17).

Although the use of evidence hierarchy and grading systems may provide an easier, or at least more streamlined, way of identifying high-quality evidence, in many situations RCTs may not be the most appropriate research methodology to answer specific policy questions, particularly in the sphere of public health. For example, findings from RCTs do not usually take into account the political, social, or economic context (18–20). RCTs may also not be a practical, or ethical, research option (e.g., research in smoking, HIV, or dementia) (21). Finally, the results of RCTs may not be easily applied to the general population or specific individuals (22). Due to these factors, policy makers often use a different hierarchy of evidence than researchers (23). For example, policy makers may consider the strongest evidence to be that from systematic reviews as they provide an overview of scientific studies which meet explicit criteria. Yet, single studies and evaluations are more commonly used to support policy than systematic reviews, possibly because systematic reviews are not available due to time constraints or lack of sufficient evidence (23).

Epidemiological data and research is typically valued highly as "objective" or "hard" data compared to qualitative data or case studies (24). Findings derived from epidemiological research are perceived to be most relevant indicator of adverse effects in humans (25) and inform public health, such as health promotion and health policy and planning (26). Public health practice is mostly based on observational epidemiological research, such as cohort, case-control, and cross-sectional studies, rather than RCTs (27). Observational epidemiological research has multiple advantages, for example a large sample size and longer follow-up periods. It can also provide a powerful argument for change by using local data and can impact policy to address emerging public health problems (28). However, epidemiological findings may not be in a form that is useful or easily understood by policy makers, for example lengthy research reports with data at a state or country level (20) or policy makers may be hesitant to use it due to chance of bias and confounding (29).

Given the importance of promptly incorporating new and robust scientific evidence into policy and the barriers to KT identified above, there is an urgent need to better understand how policy makers evaluate and use evidence. Therefore, the current study had two intersecting aims. The first aim was to gain an understanding of the role of research evidence in policy making. The second was to investigate how policy makers in the health domain select this evidence and whether they systematically assess evidence quality and how this differs from academic epidemiologists.

MATERIALS AND METHODS

An exploratory mixed-methods study design was used in order to provide a deeper understanding. The design involved the collection and data analysis of two sets of qualitative interviews ($n = 13$ and 6) and one quantitative survey ($n = 28$). Both interviews and survey are included in Supplementary Material. Written informed consent was obtained from all participants prior to involvement in the study. The Australian National University Human Research Ethics Committee (HREC) and the Australian Capital Territory (ACT) Health HREC Survey Resource Group approved the study.

Qualitative Interviews with Policy Makers
Participants and Recruitment
The first set of interviews focused on a purposive heterogeneous sample of 20 people who worked in policy. Thirteen participants were from the ACT Government Health Directorate, four participants were from non-governmental organizations, one from a national Australian government department, and two from Australia's peak research funding body, the National Health and Medical Research Council. Individuals were invited to participate in the study if they had any previous experience contributing to the development and implementation of health policy or programs relating to risk factors for chronic disease, mental health, or aging. Executive Directors from ACT Health identified participants and invited them *via* email to participate. Individuals who responded and consented to participating were then contacted by the ANU researchers. Participants were selected irrespective of policy background, time spent in organizational roles, or seniority. Participants from ACT Health were from a wide range of policy units, including Women's Youth and Child Health; Aboriginal and Torres Strait Islander; Alcohol and Other Drugs; Rehabilitation, Aged and Community Care; and Population Health.

Measures
One-on-one semi structured interviews were conducted with participants focusing on understanding: (1) how policy makers locate and use evidence from observational and other research; (2) factors influencing their choice of evidence sources; (3) how policy makers deal with conflicting evidence from specific topics; (4) how policy makers evaluate the quality of research; and (5) how policy makers view researchers. The interviews also sought information on perceived barriers to KT. The interview questions

were developed in consultation with research experts and senior staff from the health department, Alzheimer's Australia, and NHMRC. Interviews were recorded and transcribed. Interviews were done one-on-one and took approximately 1 h.

Analysis
The transcribed interviews were uploaded into NVivo (30) and thematically analyzed for themes. These themes included evidence sources, choice of evidence sources, confusion about policy, evaluating policy, grading evidence, policy drivers, policy process, policy maker concerns, and barriers affecting KT. Average and percentage calculations were also applied.

Qualitative Interviews with Epidemiologists
Participants and Recruitment
The second set of interviews focused on a purposive sample of chronic disease experts, known to the authors, who were approached to provide their views regarding the characteristics of high-quality observational research, their opinion about the currently available evidence rating systems, and the implications of grading observational research.

Measures
Participants were asked to answer seven open-ended questions in paper form seeking their views on: (1) their opinion of what constitutes high-quality observational research and how it compares with other types of research; (2) their understanding and use of current rating systems for grading evidence; and (3) the consequences of inappropriately rating observational research. Participants were provided with a one-page guide to grading instruments to clarify what the authors defined as a grading instrument (included in Supplementary Material).

Analysis
Thematic analysis using a step by step process was conducted to analyze the interviews. The interview transcripts were repeatedly screened in order to identify a list of recurring themes that appeared critical to evaluating evidence. These themes included evidence sources, choice of evidence sources, evaluating evidence, grading evidence, and observational research. Average and percentage calculations were also applied.

Quantitative Survey
Participants and Recruitment
An anonymous survey was compiled using the online survey tool Qualtrics (31). Senior staff from three health-related organizations, two government and one non-government, invited all policy makers *via* email to complete the survey. The selection of participation was not reliant on age, gender, or policy experience; however, the survey was only distributed to staff who were not involved in the qualitative interviews. Participants were not offered any incentives for completing the survey. The survey was accessible to participants for 6 months. In the time the survey was accessible, 58 participants began the survey, but only 28 participants provided responses to all questions.

Measures

The focus of the survey was barriers to knowledge-uptake, knowledge needs at the time of the survey, and the accessibility of information. The survey comprised 18 questions. Of these six were multiple-choice, five were rating scales, six were open-ended, and one was a combination of multiple-choice and open ended (included in Supplementary Material). The questions in the survey were developed after examination of surveys that had been used in related studies, consideration of results of the qualitative interviews, and after consultation with collaborators from the University, the Health Department and Alzheimer's Australia.

Analysis

Participants with missing data were excluded at the item level. Data were analyzed using Microsoft Excel. Descriptive statistics and bar graphs were used to illustrate response patterns to survey items.

RESULTS

Qualitative Interviews with Policy Makers

All but one participant (95%) reported that policies and program decisions were often based on work, including current programs or policies, which had been done in other jurisdictions or by other organizations that were presumed to have better resources for seeking evidence (e.g., work tendered to university researchers, larger organizations). In this context, respondents reported that greater emphasis was placed on the experience of running the program or implementing the policy than on the evidence base behind it, which was typically not systematically checked. As an example, one participant noted a program implemented in another state that was "taken up" and resulted in a lot of problems. Subsequent contact with those who had set up the original program revealed that they too had had a lot of problems but had not reported them.

No respondents identified a systematic approach to gathering evidence for policy. Fourteen participants (70%) mentioned that part of their research strategy included talking to experts, including academics and consultants. Eleven participants (55%) gained most of their information from consumer input and subscribed to publications by the Australian Healthcare and Hospitals Association. Academic journals and Institutional research/library services were only used by five participants (25%).

Twelve participants (60%) mentioned politics or political agenda as a significant contributor to the policy formation process. The political agenda may drive what research is used and is not, regardless of the quality of the research. For example, one participant said "... the politicians are wanting to say 'we've made a decision, this is what we're going to do'... and if there are votes in it [the politicians] will do it regardless of the evidence" (Government Health Middle Manager). Eleven participants (55%) also cited that consumer or community views were another policy driver.

Eight participants (40%) discussed that there was not a great understanding of what constitutes good or strong evidence. For example, one participant said "I think it's a bit of an issue that we've seen in terms of being able to identify well what is good evidence, what's real evidence, what evidence should you use for

a policy ... what evidence should you be using to back that up. Don't just go to a website and copy something – that happens, you know, which is not very good but it happens" (Government Health Project Officer). Policy makers identified the following as the most common factors which affect evidence choice: the type of evidence (60%), the reputation of the evidence source (55%), quality of the evidence (45%), and local applicability (40%).

Only three participants (15%) knew of grading systems and they did not use grading systems to evaluate evidence. Two of these participants discussed the mismatch between grading systems and policy, with RCTs not necessarily being applicable in the policy decision-making, but rather social research being more likely to inform a policy decision. One of the participants highlighted this mismatch and the use of systematic reviews, stating: "it's hard to find any RCTs for the issues we're after and whether they're appropriate anyway in some contexts ... in terms of policy what's really good is a Cochrane review or something that's looked at a bunch of things across everywhere and synthesized it and so then you can look at what the general opinion or picture looks like" (Government Health Middle Manager).

The most cited barriers to using robust evidence were political agenda (60%), time limits (55%), funding (50%), and research not being applicable for current policies (50%). For example, one participant stated "research takes time, as well as money and effort .... Policies have a different timeframe. So if a government is going to move in a particular area, or feels inclined or compelled that it needs to come up with something, it might not be able to wait for research" (Government Health Senior Manager) Two participants also stated that government department employees were risk averse and so would "perpetuate current practice" rather than suggesting and evaluating "original ideas" based on new research.

When policy makers were asked what could improve the use of evidence in developing policy, six participants (30%) stated that there should be more "links" or collaborations between government staff and researchers. According to one policy maker these linkages "would make policy development a lot easier because you would have shown quite clearly due to the collaborative nature of the research that you've considered a large number of things and it would seem to provide a very solid finding because of that" (NGO Manager). Two participants (10%) stated that being able to access collated information would be helpful as it would reduce the amount of time spent looking for applicable research.

Qualitative Interviews with Epidemiologists

Seven epidemiologists were asked to participate; however, only six agreed and completed the interview. All interviewees had a post-doctoral degree, and all but one was a researcher from an Australian university. There was an even number of male and female respondents.

All respondents cited that they had heard of grading system but tended not to use them to evaluate research evidence, rather they had their own way of evaluating evidence. One participant stated that they evaluated studies from first principles (clearly defined research question, clear and appropriate methods, high participation rates, appropriate analysis, and conclusions), and

another admitted to giving more credibility to studies published in prestigious journals as they tended to undergo more rigorous peer-review and methodological editing.

All respondents cited that although RCTs are considered at the top of the hierarchy of evidence and observational research lower, RCTs are not necessarily the most efficient or applicable evidence. Respondents found several problems with using RCTs, including unsuitable research questions (e.g., environmental and health-related research questions), limited generalizability, and bias. All respondents argued that it is more important to look at the design and conduct of the study – for example cohort size, duration, evaluation of relevant covariates/confounders – than it is to look at what rating the evidence is.

Responses to what constituted as high-quality observational research all focused on the rigor of the methodology. All respondents agreed that high-quality observational research should address bias and ensure that the data are valid. Four respondents also argued that the sample had to be representative of the target population and large.

Quantitative Survey with Policy Makers

The majority of respondents were aged between 35 and 44 years (32%) followed closely by 45–54 (29%) and 55–64 years (25%). Respondents were mostly female (71%) and had completed a postgraduate qualification (82%). Of the 28 participants who responded to all questions, 13 (46%) described their level within the organization as "middle management or project/policy officer with some management responsibilities."

When asked to indicate preferred research methods, respondents (19%) indicated that systematic reviews were the preferred research method. Qualitative research and RCTs followed with response rates of 16 and 13% respectively. Only 7% of respondents indicated a preference for observational research.

The most easily understood sources of evidence were trusted organizations (96%), other internal staff (92%), consumer views (85%), policies from other jurisdictions (81%), and expert opinions (73%). The most difficult evidence sources to understand were researchers and existing academic research (42%) and internal statistical data (35%).

The most important factors taken into consideration when evaluating evidence are shown in **Figure 1**. When asked to identify how often evidence sources were utilized in the policy process, the subset of policy makers (40%) who responded to this question indicated that the most often used policy sources were: existing academic research (92%), other staff within the organization (92%), similar policy experience from other jurisdictions (85%), publications from trusted organizations (73%), and guidelines (58%). The majority of policy makers from the government health department (61%) indicated that they had not used their own departmental epidemiological reports in formulating new population health-relevant policy.

The relative ranking of specific research methods and data synthesis techniques, as indicated by policy makers, is shown in **Figure 2**. Policy makers' responses to the open-ended question of what (in their opinion) constitutes high-quality forms of evidence varied. Some responses included: articles published in reputable peer-reviewed journals, RCTs that can be related to and
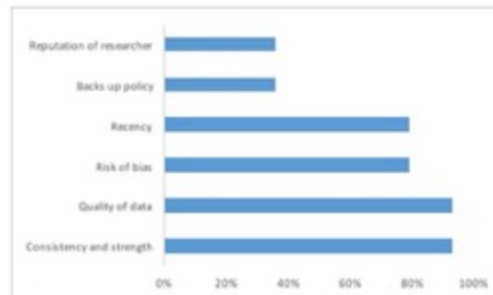
FIGURE 1 | The most important factors taken into consideration when evaluating evidence.
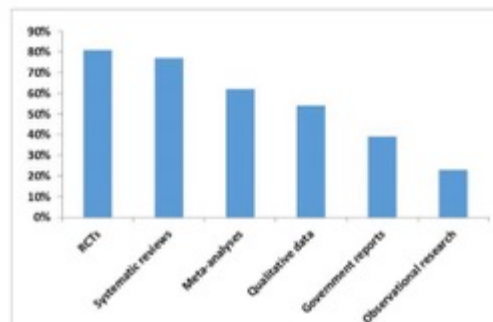
FIGURE 2 | The relative quality of specific research methods and data synthesis techniques.

translated into practical clinical guidelines, systematic reviews, case studies (depending upon the research question), and sound methodology, clearly articulated, and peer reviewed research.

DISCUSSION

The aims of this study were to gain an understanding of the role of research evidence in policy making, investigate how policy makers in the health domain select this evidence, and whether they systematically assess evidence quality. While use of evidence differs somewhat across policy makers, it appears that the reliance on direct scientific evidence in the policy development process is low. The policy maker's investigation did not seem to have a methodical approach to evaluating evidence. Although there was some overlap between what policy makers and epidemiologists identified as high-quality evidence, there was also some important differences which suggests that the best scientific evidence is not frequently used in the development of policy. Differences between epidemiologists and policy makers included the way evidence was evaluated and the importance placed on study's methodology.

What Evidence Do Policy Makers Use in the Policy Process?

Systematic reviews were the preferred research method in the policy-making process. Observational research came last and ranked as the lowest quality. Previous research has found that policy makers perceived systematic reviews as better suited to identifying gaps in existing research rather than providing answers to policy questions (32). This research also found that systematic reviews were useful only when they had been commissioned to support policy decisions that had already been made, rather than inform the decision-making process of which policy option is most effective. Systematic reviews may be favored by policy actors because of their potential to save time and other resources and are seen as a credible source of information.

The information provided by policy makers about the use of academic resources in the policy process is inconsistent. In the web survey, all responding participants indicated that academic research was the most often utilized evidence source in the policy process. However, in the interviews, only one-quarter of participants stated that they referred to academic journals when gathering evidence for policy. Furthermore, participants from the web survey stated that academics and existing academic research were the most difficult evidence source to understand. This difference between responses may indicate that what policy makers think they are using, or what they should ideally be using, is not what they actually use and that they may not fully understand the academic research that they are using. Studies that had similar results found that respondents did not use academic literature because they did not have access to libraries or online journals, they were not trained in how to use academic search engines and because they found academic literature complex and frequently contradictory (15).

Results from both the web survey and interviews found that the majority of policy makers used work which had been done by other jurisdictions or organizations as a base for policy and program decisions. The use of other jurisdictions programs/policies may be a feasible option as it fits with the policy environment and provides a sense of security that the intended outcomes will be achieved within the decided timelines. However, as participants pointed out, this transferability either may not be applicable to the adopting jurisdiction or key information and supporting evidence may not be provided by the other jurisdiction. Given that respondents stated they usually did not check the quality of the evidence to these programs, or the applicability of this evidence to the situation, then the policy/program objective may not be met.

Respondents from both the interviews and web survey also mentioned that other internal staff members were one of the most frequently utilized source of evidence, and that part of their research strategy included talking to others, such as experts or consultants. This has been found in previous studies and may be a way of gaining accurate information quickly (9, 14, 33).

Policy maker's reliance on peers and other jurisdictions, rather than evidence, could indicate several possible characteristics of policy makers. First, this might suggest that respondents are assuming that someone else has checked and evaluated the evidence. Second, policy makers may lack the skills to evaluate the evidence themselves, or lack confidence in their own skills. A third possibility, cited by two participants, is that individuals within the government health department are risk averse. Individuals may feel that the culture within the public service discourages innovative programs and policies as such evaluations may fail and result in damage to the government and individual's reputations.

Previous research has found that political opinion or targets influenced the adoption of particular policies or programs (13). Within this study, most policy makers mentioned politics or political agenda as a significant driver in the policy formation process, followed closely by consumer or community views. In Ritter's study (15), they found that the internet, notably "Google," and statistical data were the third and fourth most frequently mentioned source used by policy makers. Policy makers did not mention the use of the internet in our quantitative survey, and only one participant mentioned it in the qualitative interviews. The majority of respondents in our study indicated that they did not use their own departmental epidemiological reports. Our results may differ from Ritter's because we did not explicitly ask about internet or statistical data use or because participants were hesitant to discuss their usage of these sources.

How Do Policy Makers Evaluate the Quality of Evidence and How Does It Compare to Epidemiologist's Evaluation?

Just under half of participants in the interviews discussed that there was not a great understanding among policy makers of what makes good quality evidence. This has been found in previous studies (23). Although some respondents had heard of grading systems, neither the policy makers nor epidemiologists whom we interviewed used them. Rather, policy makers and epidemiologists had their own way of evaluating evidence. Although grading systems may not identify the most appropriate research methodology, their usage enables a standardized, comprehensive, transparent, and easily communicated way of rating the quality of evidence for different policy decisions and the strength of recommendations and could improve decision-making processes (34).

Both parties agreed that RCTs, followed by systematic reviews, provided the highest quality evidence and that observational research was ranked the lowest. However, both policy makers and epidemiologists cited problems with using RCTs in their respective fields. For policy makers, RCTs were not applicable in the policy decision-making process, whereas epidemiologists had methodological issues with RCT designs (e.g., limited generalizability and bias). These findings are similar to previous research (20, 23).

Barriers to Use of Evidence in Policy Making

The most cited barrier to using robust evidence was political agenda and time limits. Previous research has also found that the short time periods, or need for action, within the policy making sphere meant that decisions were often made whether "strong"

evidence was there or not (13, 35). Research can take up to 3 years to be published following data collection, so by the time it is made available the information may be out of date or less useful to policy makers (4).

Half of our policy-maker participants stated that barriers to using research were lack of funding and research not being applicable to current policy. This has been found in previous research (35, 36). It has been suggested that in order to overcome these barriers there should be a dialog between researchers and policy makers before the study design is carried out. As policy decisions may be influenced by pragmatic considerations, such as cost (13), then, researchers should be made aware of these considerations and build research and recommendations that accommodate them.

Enablers to Use of Evidence in Policy Making

The establishment of more links, or collaborations, between policy makers and researchers was cited by one-third of policy makers as a way to improve the use of evidence in the policy-making process. This strategy has been frequently discussed in previous research (7, 35). Previous research has identified that policy makers use sources that are highly accessible and prefer summative information that uses plain language and clear data (7, 15). Two policy makers in our study discussed having access to evidence collated within a single source. We think this type of information source would not only reduce the amount of time policy makers spend gathering evidence but could also be used to help policy makers identify strong evidence, based on the methodological considerations discussed by epidemiologists in this study. The authors have developed a web-based tool designed to help policy makers find and evaluate evidence (37). This tool will integrate the epidemiologists and policy makers on observational evidence and provide policy makers with the skills needed to understand and critically appraise research, which is a specific practice of KT (3).

This study has some limitations. First, the sample size was small and only a few organizations within a single Australian provincial-level jurisdiction were surveyed and as such may not be more widely generalized. Second, due to survey design, we could not analyze how policy maker's level of research training affected their use of scientific research. For example, it is possible that those with a specific health-related Masters or Postgraduate degree are more likely to use peer reviewed literature. Despite these limitations, this study gathered data on a process about which little is known or understood. Furthermore, it used different methodologies in order to gain a more comprehensive understanding of the issue and different organizations from both government and non-government were involved.

Recommendations
For Policy Makers

To facilitate the use and assessment of academic research in the policy-making process, we have four recommendations. The first is to build policy makers capacity to appraise evidence, through strategies, such as training and participation in internships. This recommendation is based on our finding that policy makers did not have a great understanding of what makes good quality evidence nor did they use a standardized way of evaluating evidence. As only a small number of policy makers in this study referred to academic sources, the second recommendation is to ensure that policy makers can access robust sources of scientific evidence, for example online peer-reviewed journals. Third, because the policy and scientific processes occur on different time scales, which policy makers in this study cited as a barrier to using robust evidence, the sharing of evidence between researchers and public servants should be facilitated through new channels and ways of conducting business. This is particularly important for health issues for which the scientific data may vary substantially over time. Finally, we recommend developing mechanisms through which scientists with specific expertise are invited into a particular department for a "scientific chat" to openly discuss planned policies. This would be particularly useful in cases where commissioning new research would take too long but where substantial "soft" evidence is already available in the scientific field.

For Researchers

Based on our findings that policy makers cited researchers and existing academic research as one of the most difficult evidence sources to understand and that a barrier to using robust evidence was research not being applicable to current policies, we have three recommendations for researchers. The first is to build awareness among researchers producing policy-relevant material that this information cannot be communicated exclusively through typical scientific dissemination processes (e.g., conference presentation, peer-reviewed publication). Furthermore, academic research with policy-relevant material should include a clearly identified policy-relevant section that can easily be identified by policy makers, and the language and statistics included should be tailored in a way that makes them usable by policy makers. Second, training on the production and effective ways to communicate policy-relevant material in scientific research should be provided to researchers. Finally, forums where scientists and policy makers can interact and demonstrate their viability and effectiveness should be established.

CONCLUSION

This study has found that neither policy makers nor epidemiologists are using grading systems to evaluate evidence, rather each have their own ways of assessing the evidence. Both policy makers and epidemiologists recognized that RCTs were usually at the top of these hierarchies, but that RCTs were not always the most efficient or applicable evidence upon which to base population health policies and that there were some problems with RCT designs. Policy makers in this study demonstrated a good understanding that they need to have an evidence base, that it is an important part of the process, and that it justifies the policy. However, the time and resources to form that evidence base, as well as an understanding of what constitutes good evidence and

how to evaluate it was lacking. This study is limited by its small sample size; however, by having both in-depth interviews and the web survey we are provided with more and often conflicting information than previous research has found using just survey data. Finally, this study focused on the use of observational evidence and interviewed only one type of public health researcher, academic epidemiologists. By using this approach, the authors have not examined the use of intervention research which provides direct evidence on how to produce change and which may be more relevant to policy makers (38). Findings from this study demonstrate that scientific information needs to be more systematically available to policy makers and that efforts should be directed toward increasing the communication between researchers and policy makers.

AUTHOR CONTRIBUTIONS

The study concept and design was done by KA, NC, and PK. All authors contributed to the analysis and interpretation of data and drafting of the manuscript. LJ conducted all statistical analysis. All authors have read the final paper and have agreed to be listed as authors.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at http://journal.frontiersin.org/article/10.3389/fpubh.2016.00267/full#supplementary-material.

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4.4 Knowledge Translation Frameworks

Policy makers are under increasing pressure from politicians to ensure decisions and policies are evidenced-based, however, previous research has identified significant barriers to this process. One way to address these barriers and increase the use of scientific evidence in policy and practice decisions is through the process of KT. The most commonly used definition of KT from the Canadian Institutes of Health Research has been provided in the literature review (Chapter 2). KT is mostly conceptualised as the various strategies or activities, active or planned, which could be adopted to increase the impact, or use, of research on policy and practice decisions (Davison, 2009; Rychetnik et al., 2012). Fundamentally, it is the process of linking between researchers and individuals who use research to make decisions (Shantz, 2012).

There are four key models which drive the KT process between researchers (producers) and policy makers or clinicians (users) (National Collaborating Centre for Methods and Tools, 2011; Oxman, Lavis, Lewin, & Fretheim, 2009). These models can be used either singly or in combination (Lavis, Lomas, Hamid, & Sewankambo, 2006). The first model is the 'science push model,' also termed 'push efforts' or 'technological model' (Landry, Amara, & Lamari, 2001). This model emphasizes researchers supplying, or 'pushing,' their research findings and knowledge to users. Within this model the use of evidence follows a linear sequence- researchers supply knowledge and policy makers and practitioners use it (Landry et al., 2001).

The economic model, also referred to as 'user pull efforts,' stresses user-driven research (Landry et al., 2001; Lavis et al., 2006). This model also follows a linear sequence. However, in the economic model the user identifies and directs the research they want from the researcher. In this model the use of knowledge is increased when researchers focus their studies on the needs of the user rather than just the advancement of scholarly knowledge (Landry et al., 2001).

The third model, termed 'exchange efforts,' emphasizes partnerships between producers and users. The rationale of this model is that users will be more likely to use research if they are actively

involved and can guide research to answer specific contextualised questions (Grimshaw, Eccles, Lavis, Hill, & Squires, 2012). Deliberative Dialogues and the use of knowledge brokers are examples of exchange efforts (Grimshaw et al., 2012; Horvath et al., 2017).

The fourth model, the integrated model, also termed the 'social interaction' or 'interaction model,' was developed to overcome the criticisms of the previous three models. This model includes elements of the push, user pull and exchange approaches (Lavis et al., 2006). It emphasizes the interaction between users and producers and predicts that the more sustained and intense the interaction between them, the more likely it is that research will be utilised (Landry et al., 2001).

The four models explained above are included in a KT framework developed by Lavis et al. (2006) to support the use of research evidence to inform health policy decisions (discussed below). However, there are other conceptual models and frameworks which are recommended as a way of applying theory and increasing the impact of research on health policy and/or programs. Frameworks provide a frame of reference for organising thinking, a guide for action and interpretation. By applying a framework the process of KT is more systematic and there is a greater likelihood of changed practice and spread of evidence (Field, Booth, Ilott, & Gerrish, 2014).

An in-depth analysis and comparison of all the different frameworks is not necessary in this thesis. However, to provide an understanding of the KT process a brief outline of six frameworks will be provided. These six frameworks have been selected because of their applicability to public health policy and are frequently cited in the KT literature. The frameworks to be discussed are:

1. The Sax Institute model

2. Translational framework for public health research

3. Framework for research dissemination and utilization (RD&U)

4. Knowledge to action (KTA) framework

5. Framework for consideration of evidence and context in the development of health policy recommendations

6. Linking research to action (Linking RTA)

These frameworks are specific to health and can be used to increase the impact on research on health policy and/or programs. Elements from each of these frameworks are incorporated into the WHO's Ageing and Health KT framework which is described in detail below.

1. The Sax Institute Model (Redman, Jorm, & Haines, 2008)

The Sax Institute Model focuses exclusively on the use of evidence from research in health policy. The model argues that the use of research in health policy involves complex interactions between policy makers, researchers, universities, research funders, government and the wider community (Moore et al., 2009). The model describes attributes of each actor involved in KT (policymaker, researcher and their respective institutions) that will promote use of research in policy. The model also illustrates enablers and tools that will increase policymakers' access to research and the production of policy-relevant research. The model describes a feedback loop where increased use of research in policy stimulates greater demand for policy relevant research (Redman et al., 2008)

Enablers and tools identified in the model include research infrastructure, such as databases, cohorts or registers, to increase the production of new policy relevant research (Redman et al., 2008). It also identifies tools to increase access to existing evidence from research, including research summaries. Finally, the Sax Institute has developed tools to increase partnership and exchange between policy makers, service provides and researchers. The Institute has developed other tools to increase exchange and collaboration by providing informal opportunities for sharing information, structures for promoting exchange (e.g. hosting seminars or forums around specific topics) and brokering research partnerships between policy makers and researchers (Redman et al., 2008).

2. Translational framework for public health research (Ogilvie, Craig, Griffin, Macintyre, & Wareham, 2009)

This framework was developed to demonstrate the complexity of the knowledge translation process in public health and show how this differs from the more linear medical model of KT (Moore et al., 2009). The framework recognises that a wide range of evidence may influence public health action, including research at individual and collective levels and from different disciplines. The framework identifies that the process of evidence synthesis is fundamental to presenting evidence in a way that can inform policy and practice. Within this framework the desired endpoint is population health improvement, including changes in health-related behaviour, morbidity, mortality and quality of life (Ogilvie et al., 2009). Population health surveillance data from these endpoints can then be used to inform new research and policy.

3. Framework for Research Dissemination and Utilization (RD&U) (Dobbins, Ciliska, Cockerill, Barnsley, & DiCenso, 2002)

The framework for Research Dissemination and Utilization (RD&U) was developed by Dobbins et al. (2002) for both health policy makers and clinical decision-making. The framework portrays the use of research in decision-making to be complex and influenced by four main factors: innovation, organisation, environment and the individual characteristics (World Health Organization, 2012).

The framework highlights the characteristics at each stage of the innovation adoption process, while integrating the concepts of research dissemination, evidence based decision-making and research utilization. The five stages of innovation include knowledge, persuasion, decision, implementation and confirmation (World Health Organization, 2012). During the persuasion stage four types of characteristics (innovation, organisation, environment and individual) can influence the

progression from research dissemination to research utilization. The five stages may not occur linearly and may be multidimensional (Dobbins et al., 2002).

4. The Knowledge-to-Action (KTA) framework (Graham & Tetroe, 2009)

The KTA framework was developed by members of the Canadian Institutes for Health research and focuses on researchers moving research evidence into health policy and practice (Moore et al., 2009). The knowledge-to-action (KTA) framework is comprised of two concepts: knowledge creation and the action cycle, each of which contain several phases (World Health Organization, 2012).

Knowledge creation is represented by the 'knowledge funnel.' The three phases in the funnel include knowledge inquiry (the large number of primary studies and other information), knowledge synthesis (aggregated knowledge such as systematic reviews) and knowledge tools or products (synopses such as practice guidelines or decision aids that present knowledge in clear formats and provide recommendations) (Cook & Rockwood, 2013; Graham et al., 2006). As knowledge moves down the funnel it becomes more refined and tailored, as if sifted through filters, so that by the end only the knowledge most useful to stakeholders remains (Graham et al., 2006).

The action cycle is concerned with implementation of the knowledge (Cook & Rockwood, 2013). There are seven phases in the action cycle, which may occur sequentially or simultaneously and may be influenced by the knowledge phases (Graham et al., 2006). These seven phases are i) identifying the problem and identifying, reviewing and selecting the appropriate knowledge, ii) adapting or applying the knowledge to the local context, iii) assessing the potential barriers to knowledge use, iv) determining appropriate actions or interventions, v) monitoring the knowledge, vi) evaluating the outcomes and vii) sustaining the knowledge use (Cook & Rockwood, 2013; Graham et al., 2006; Moore et al., 2009; Straus, 2009). The KTA process is complex and dynamic. There are no definite

boundaries between knowledge creation and the action cycle, the phases may occur sequentially or simultaneously and may influence each other (World Health Organization, 2012).

The KTA framework includes the key elements of evidence, context and facilitation. It emphasises the ongoing exchange and communication between researchers and research users. The degree of engagement between researchers and research users is dependent on the strength of the evidence, how relevant and applicable it is to their needs, and whether it is tailored for the local context (Moore et al., 2009).

5. Framework for consideration of evidence and context in the development of health policy recommendations (Dobrow, Goel, Lemieux-Charles, & Black, 2006)

Dobrow et al.'s (2006) framework for consideration of evidence and context in the development of health policy recommendations emphasises the importance of internal and external contextual factors in determining what constitutes evidence and how that evidence is used in different types of policy making. Internal factors may include key policy objectives, decision support tools and individual skills or abilities. Examples of external factors include political interests and constraints in resources. The internal and external context will affect the identification, interpretation and application of evidence (Dobrow et al., 2006). Internal contextual factors are open to change, whereas external factors tend to act as barriers or limitations. The type of evidence considered to be the most relevant will change depending on the policy objective. Decision support tools, such as agreed decision principles and evidence hierarchies, may assist in using evidence in the decision-making process (Moore et al., 2009).

6. Linking Research to Action (Linking RTA) (Lavis et al., 2006)

Developed by Lavis et al. (2006) the Linking Research to Action (Linking RTA) framework provides a range of activities that can be used to support the use of research evidence to inform health policy

decisions when organisations are developing initiatives (World Health Organization, 2012). The framework has four elements: the general climate for research use, the production of research that is highly relevant to and appropriately synthesised for policymakers, efforts used to link research to action and approaches to evaluation (Oxman et al., 2009; World Health Organization, 2012). The third element, efforts used to link research to action has four activities. These four activities are 1) push efforts (e.g. researchers identifying actionable and tailored messages to policymakers), 2) facilitating pull efforts (e.g. developing websites that provide systematic reviews or rapid response units), 3) user-pull efforts (e.g. teaching policy makers how to access research), and 4) linkage and exchange efforts (e.g. having a partnership between researchers and policymakers, either through a knowledge broker or independently) (Lavis et al., 2006; World Health Organization, 2012).

Although these six frameworks stem from different theories, several have many concepts in common (World Health Organization, 2012). Common themes in KT frameworks include the concept that KT is varied and multidimensional, KT involves interaction between evidence producers and users and that there are barriers and facilitators to KT (Davison, 2009). All these frameworks acknowledge the difficulties of closing the gap between research and policy or practice. This gap is partly due to research failing to meet the information needs of policy makers or practitioners and researchers not giving sufficient attention to real-world contexts (Milat & Li, 2017). Several of these themes are reflected in the framework described below.

4.4.1 World Health Organization Ageing and Health Knowledge Translation Framework

The following section discusses the WHO Ageing and Health Knowledge Translation (KT) Framework in detail. This framework can be applied specifically to the research discussed in this thesis as it includes factors deemed important to the fields of ageing and health and reflects the differing elements, in order of importance, with respect to facilitating the use of research evidence in policymaking in the area of ageing and health. Certain contextual factors, relationships and

initiatives specific to ageing and health are included in this framework (World Health Organization, 2012).

The WHO Ageing and Health KT framework is based on Lavis et al's (2006) Linking RTA framework, discussed above, modified to include elements specific to the ageing and health field. The main elements of the framework are: 1) a climate and/or context for research use; 2) linkage and exchange efforts between researchers, stakeholders and research users; 3) knowledge creation; 4) push efforts; 5) facilitating pull efforts; 6) pull efforts; and 7) evaluation of efforts to link research to action.

The first element, the climate and context for research use, considers the local context, including the political and social context, and its characteristics with respect to ageing and health as well as existing or potential KT activities. Assessment of the context is based on a series of questions, for example are there policies related to ageing and health or do existing health policies relate to ageing? Do the health systems, intermediary groups and research users emphasize the value of research use in the policymaking process?

The second element, linkage and exchange efforts, focuses on the collaborative relationship between policymakers, stakeholders and researchers. For linkage and exchange to be beneficial the parties involved need to be committed to working together to ask, analyse and answer policy-relevant questions. Positive linkage and exchange includes activities such as regular meetings between government and non-government staff. In these activities, research presentations and interactive workshops could take place and "deliberative dialogues" on policy-related issues can occur.

Knowledge creation, the third element, is concerned with creating research that is relevant and timely. This can be achieved through initiatives such as the establishment of gerontology and geriatrics research centres or research centres that carry out research on issues on ageing. It can also be achieved by ensuring access to and linkages with databases and national statistics

bureaus/census data, and participation by health systems in regular priority setting processes related to research on ageing and health.

The fourth element is concerned with researchers using 'push efforts' to bring research evidence that may inform the policy development and implementation processes to the attention of policymakers. Examples of 'push efforts' include identifying actionable messages from research, modifying the message for different user-groups, disseminating the message by working with a credible messenger for each group, and then using research informed strategies to encourage and support decision-making and actions associated with the messages. A limitation of push efforts is that researchers may promote individual studies, especially their own, to healthcare professionals and/or policy makers. Individual studies may contain biased findings which are misleading and rarely provide sufficient evidence for policy or practice changes (Grimshaw et al., 2012). Grimshaw et al. (2012) suggest that up-to-date systematic reviews or other syntheses should be the basic unit of knowledge translation.

The fifth element, facilitating pull efforts, is aimed at making it easier for managers and policymakers to identify relevant research. Initiatives that may facilitate pull include health systems ensuring staff have access to a network of ageing and health experts, and that they implement a technical infrastructure or 'one-stop shopping website' to support research use. For example, providing research in a 1:3:25 format (1 page of take-home messages, a 3-page summary and a 25-page report) can be one way of facilitating both push and pull efforts. Pull efforts are when policymakers are using the relevant evidence in the policymaking process. A limitation of pull efforts is when policy makers will 'pull' evidence selectively for political purposes, such as supporting decisions that have already been made or using research that fits with existing political values (Morgan-Trimmer, 2014).

Ways to increase pull efforts include health systems instituting policies that require the use of evidence in policymaking, using rapid response units that have access to experts on ageing and

health who can provide summaries of relevant research in a timely manner, and engaging knowledge brokers to assist in acquiring, assessing, adapting and applying research in the policy decision-making process.

The final element of the framework, evaluation of efforts to link research to action, is concerned with the monitoring and evaluation of KT efforts. In order to evaluate KT effort, health systems need to allocate resources and funding to the evaluation of the impact of evidence informed decision-making and monitor implementation.

4.4.2 World Health Organization Knowledge Translation Framework in the ACT Context

To highlight elements of the WHO KT framework, some examples of KT processes from the author's local context are discussed, including the partnership between researchers from the ANU and policy makers from the ACT Health government department. More discussion on how this partnership facilitated KT is provided below.

The first element is that there is a climate and context for research use, including the political and social context, and its characteristics with respect to ageing and health as well as existing or potential KT activities. Within the ACT, policies that relate to ageing, both specifically and generally, are found across government. The ACT Government has developed several strategic frameworks which outline the ACT Government's priorities for the ageing population. For example, the ACT Strategic Plan for Positive Ageing 2010-2014 and the ACT Active Ageing Framework 2015-2018. In both these documents the objective for health in the older population is concerned with enhancing health delivery services and supporting seniors to develop healthy lifestyles.

Currently, the Rehabilitation, Aged and Community Care Policy Unit in ACT Health is developing a Dementia Service Action Plan which will examine strategies required to support the ACT Health system respond effectively to the needs of people with dementia, their carers and families into the future. The ACT Dementia Services Action Plan will contain information based on consultation with key stakeholders, including researchers, service providers, clinicians and consumers, as well as the

National Framework for Action on Dementia 2015-2019 (Aged and Community Care Policy Unit, 2016).

An example of the second element of the framework, linkage and exchange efforts, is that researchers from the ANU have an established relationship with managers and staff from the Health Promotion Branch, ACT Health Directorate. This relationship has resulted in collaborative projects and reciprocal secondments. More broadly across ACT Health, researchers from the ANU have given several presentations about available research and datasets and held workshops about research methods and how to best communicate their research to policy makers. The aim of these efforts is to promote increased involvement of ANU in the development of policies and programs and that staff from ACT Health will become active in the development of future research.

Knowledge creation, the third element of the framework, is concerned with creating research that is relevant and timely. By way of example, CRAHW, established in 2012, at the ANU is a research-intensive centre which focuses on the well-being of individuals and communities throughout the life course. The centre has particular expertise in cognitive ageing and dementia, social gerontology and healthy ageing. Principal investigators from the Centre conduct the PATH study. The PATH dataset has the potential to be linked to a number of datasets, both national and ACT specific, including the Medicare Benefits Schedule, the Pharmaceutical Benefits Scheme, ACT mortality data and ACT Admitted Patient Care data (see Chapter 3 for more information). The research and the findings presented in this thesis were designed to be applicable to the local context, relevant to policy and practice, and provide guidance for future policy making and practice actions.

Researchers from the ANU have tried to facilitate both push and pull efforts, the fourth and fifth elements of the framework in a number of ways, including by communicating their research in an accessible format to policy makers. For example, paper 1, included earlier in this chapter, was

provided to staff at ACT Health government in a 1:3:25 formatted document to ensure that the research was accessible to all staff levels (Francois, Eramudugolla, Cherbuin, & Anstey, 2015).

The ACT Government and researchers from the ANU are also continually evaluating their KT efforts. For example, the ACT Health Directorate has a section, Population Health Research and Evaluation Section, whose purpose is to provide support for research and evaluation across the Department. In 2012 the ACT Health Directorate developed the first Population Health Research Strategy for the ACT. This strategy has a number of key activities, one of which is to develop a knowledge transfer framework to ensure successful transfer of knowledge and exchange information between various stakeholders (ACT Health Directorate, 2014).

4.5 Barriers and Enablers of Knowledge Translation

Some of the frameworks discussed above include specific factors that either support or work against the process of KT (Davison, 2009). Most KT models suggest that KT is more likely to be successful if an assessment of the likely barriers and facilitators informs the choice of KT strategy (Grimshaw et al., 2012). Depending on how a factor is managed it can be either an enabler or a barrier. For example, a good working relationship between researchers and policy makers can enable translation of knowledge by building trust, but a poor or non-existent relationship could be a barrier as it results in mistrust of the other party. Outlined below are three of the most reported barriers and enablers of knowledge translation: resources, differences in work, communication and motivations, and the relationship between researchers and policymakers.

4.5.1 Resources

A significant barrier, and predictor of success, to incorporating research into public health decision-making is adequate resources. This includes four interconnected resources of money, time, access and skills (Dobbins, DeCorby, & Twiddy, 2004; McWilliam et al., 2009). These four resources

are required to identify, retrieve, read, synthesize and translate available evidence into policy

(Dobbins et al., 2002).

The first resource is money. Sufficient funding is important for generating relevant research

(Campbell et al., 2009). In paper 1 (Chapter 4) we found that 50% of policy makers felt that funding

was a barrier to using robust evidence in making decisions. Similarly, a systematic review found that

7 out of 24 research papers mention power and budget struggles as a barrier to using robust

evidence (Innvaer et al., 2002). Shortage of funds for research and evidence explicitly produced for

policy makers is a factor preventing the development of evidence based policy making (Majdzadeh,

Yazdizadeh, Nedjat, Gholami, & Ahghari, 2012).

The second resource is time. The article in the previous chapter found that, along with funding,

one of the most reported barriers to using robust evidence was time limits. Researchers and policy

makers have different timeframes (Majdzadeh et al., 2012). Policy makers require decisions to be

made in short time periods, whereas reliable and high-quality research requires long periods of time.

Research projects frequently take 3 to 6 years to complete and it may take as many as 8 to 10 years

from the time of the initial hypothesis to dissemination of findings (Brownson, Royer, Ewing, &

McBride, 2006). The long timeframe required for quality empirical evidence can limit the potential

impact of research on immediate policy problems, for example by the time robust research is

available the political and social climates may not be receptive or the issues may have changed or

disappeared entirely (Brownson et al., 2006; Marston & Watts, 2003).

Policy makers have also identified that there is very limited time to locate, appraise, synthesize,

interpret and incorporate research evidence into decision-making (Dobbins et al., 2004). There is an

increasingly large number of research articles produced every year and it is not possible for policy

makers to be aware of the latest research or to have the capacity to evaluate this research (Draper,

Low, Withall, Vickland, & Ward, 2009). Further difficulties arise from diversity in the fields of

research, the different needs of policy makers and research being presented in a way that is time

consuming to extract information from, for example in a long paper with a large amount of statistical analyses. As evidenced in previous studies, policy makers prefer systematic reviews or summary documents which are easy to read and provide recommendations (Dobbins, Rosenbaum, Plews, Law, & Fysh, 2007; Innvaer et al., 2002). However, policy makers have cited that they often find it difficult to access brief summaries and systematic reviews (Campbell et al., 2009). This may be due to lack of physical access to research, for example due to scientific journals requiring subscription to access the contents of scientific literature, or to the lack of systematic reviews that provide relevant and up-to-date research (Cvitanovic et al., 2015).

Policy makers also identify that the timing for receiving research is important. Policy makers are more receptive to receiving and using research evidence when it is directly related to issues that are currently being considered (Dobbins et al., 2004). The lack of timeliness or relevance of research has been cited as a barrier, with policy makers finding that the research available is not relevant to current policy issues, or does not inform policy development in the area required (Campbell et al., 2009; Innvaer et al., 2002; Oliver et al., 2014a).

Policy makers may not have the skills or abilities, or lack the experience, to assess and utilise evidence (Dobrow et al., 2006; Majdzadeh et al., 2012). Policy makers receive information from a variety of sources and have identified that they are overwhelmed by how to categorise and assimilate this information (Dobbins et al., 2004). It has been suggested that policy makers need to be provided with more training on how to understand and use different types of research. To facilitate the use of research in policy making, researchers need to develop skills on how to best communicate their findings and more understanding of the policy process, including how research informs policy (Black, 2001; Macintyre, 2012). Researchers need greater access to information on the priorities of policy makers, who in turn need to organise and communicate their needs better (Black, 2001).

4.5.2 Differences in Work, Communication and Motivations

Failures in the KT process have often been attributed to policy makers and researchers living in two separate worlds, termed the 'two communities' theory (Jacobson, Butterill, & Goering, 2004b). The 'two communities' theory argues that policy makers and researchers have different logics, incentives, values and speak different languages (Wehrens, 2014).

The first difference between policy makers and researchers is the incentive system or motivations in each workplace. The incentive system in universities has been cited as a barrier to KT as there is no reward for knowledge translation (Shantz, 2012). For academic researchers, their career success and funding depends on publishing in peer-reviewed journals and acquiring academic research. This is divergent to the needs of potential research users (Mitton, Adair, McKenzie, Patten, & Perry, 2007). Within policy making organisations, such as government, process and power flow from the top down. Policy makers' careers are dependent on advancing policies and programs that reflect the values and attitudes of the government (Gibbons et al., 2008). A challenge for both researchers and policy makers is that knowledge about how to evaluate the success of knowledge translation efforts may be lacking, ranging from simply forming a relationship between the two groups to research influencing a policy. Evaluating the impact of research may take a long time and success is difficult to define. The inability to clearly demonstrate any return on investment of knowledge translation efforts is detrimental when researchers or policy makers are trying to demonstrate the value of their efforts (Shantz, 2012).

The second difference between policy makers and researchers is the language and communication style used, especially in the dissemination of research findings. The primary way researchers communicate their findings, via peer-reviewed journal articles or conference presentations, may impede the use of research in policy making. The primary outputs of research tend to have a high volume of data, or statistical analyses, use complex scientific language and lack actionable messages or implications. These outputs, as discussed above, may not be easily

understood by policy makers and the relevant information may be hard to extract (Brownson et al., 2006; Mitton et al., 2007). By disseminating their research findings in this manner there is also a lack of direct, face-to-face communication between researchers and policy makers which may lead policy makers to misinterpret research findings (Mitton et al., 2007).

The final difference is the culture within each organisation. Within government there may be political uncertainty and high staff turnover. These two factors can affect the use of evidence in decision-making by limiting awareness of the importance of using evidence and having incentives that are stronger than evidence based decision-making (Majdzadeh et al., 2012). Politics influences decision-making in government, with some political interests affecting the extent to which policies are based on research (Flitcroft, Gillespie, Salkeld, Carter, & Trevena, 2011; Hyder et al., 2011). Staff turnover can result in the 'broken link' phenomenon, whereby a researcher establishes a good working relationship with a policy maker only to have that individual move to another position and be replaced by someone with little or no content knowledge (Dwan & McInnes, 2013; Shantz, 2012). The regular movement of departmental staff between positions results not only in loss of knowledge and capacity but can also be a barrier to the formation and continuity of partnerships between research producers and users (Dwan & McInnes, 2013; Gleeson, Pfeffer, Legge, & O'Neill, 2011; Traynor, Dobbins, & DeCorby, 2015).

Policy makers' response to research varies within organisations. This variation is not just with the type of issues and research being considered but also the different attitudes towards the policy-making process, with some individuals more receptive to research than others (Hanney, Gonzalez-Block, Buxton, & Kogan, 2002). One study found that the use of evidence in making decisions has not yet been incorporated as a priority in the policy making environment, creating a non-supportive culture for evidence based policy making (Majdzadeh et al., 2012). Furthermore, officials in a policy making organisation may be resistant to research based on mistrust of information generated outside the organisation or system (Hanney et al., 2002). The use of research in policy making could

be enhanced by a government culture that trusts and understands the value of research (Mitton et al., 2007), for example organisations that have senior administrators with prior research experience or interests have stronger connections between policy and research (Hanney et al., 2002). However, policy making decisions will also depend on how much the research accords with the political and social priorities at the time, the political and administrative priorities and the institutional arrangements for policy making (Hanney et al., 2002).

4.5.3 Relationship between Researchers and Policymakers

One of the most widely referenced enablers of KT is the interface and relationship between policy makers and researchers (Innvaer et al., 2002). However, in a study by Head, Ferguson, Cherney, and Boreham (2014) 56% of public officials reported that there was little opportunity to build relationships with researchers outside the public service and 39% said that their department had no formal processes to translate academic research into policy. Improving engagement between researchers and policy makers may result in evidence being used in the policy making process. Engagement can be improved two ways. Firstly, having a relationship may result in mutual understanding of what motivates the other and the differences in workplace environment (Gibbons et al., 2008). Such an understanding may then result in collaborative development and use of research in the policy making process. For example, in a study by Haynes et al. (2011) 91.5% researchers said that having an understanding of policymakers' needs and constraints helped them to influence policy.

Personal relationships between policy makers and researchers are an important aspect of having a partnership (Gibbons et al., 2008). By developing a relationship or interface, differences in values and interests between the two-communities and their different time-frames may be overcome (Hanney et al., 2002). Researchers may learn about the current key policy issues and provide relevant research. They can also help raise policy makers' awareness of other important issues that are addressed in research (Hanney et al., 2002).

Secondly, developing a relationship between researchers and policy makers may enhance trust between the two groups (Haynes et al., 2011). The lack of trust between researchers and policy makers is a barrier to KT and a significant reason why there is a gap between the two groups (Majdzadeh et al., 2012). Researchers are perceived as politically naïve and policy makers are perceived as scientifically naïve (Innvaer et al., 2002).

4.6 Paper 2: The use of secondments as a tool to increase knowledge translation

Many of the KT frameworks emphasise interactions between researchers and policy makers to facilitate communication and the use of research in policy and practice. For example, the Sax Institute model (Redman et al., 2008), KTA framework (Graham & Tetroe, 2009), Promoting Action on Research Implementation in Health Services framework (Kitson et al., 2008), Participatory Action KT model (McWilliam et al., 2009) and the WHO Ageing and Health KT framework (World Health Organization, 2012). One approach to increasing the interaction or improving the relationship between researchers and policy makers is through the implementation of secondments (Ward, Smith, Foy, House, & Hamer, 2010) or by embedding researchers in decision-making departments (Cvitanovic et al., 2015). A secondment, or internship, is when an employee temporarily changes their job role, or relocates within the same organisation or to another organisation for an agreed period of time either on a full-time or part-time basis (Hamilton & Wilkie, 2001). The following manuscript discusses the experience of a reciprocal secondment between two organisations, the ANU and the ACT Health Directorate. The article discusses how secondments could increase KT and strengthen relationships between organisations.

Statement of authorship

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Responsible for collecting data, and for designing, writing and editing the manuscript. Acted as corresponding author. I certify that the statement of contribution is accurate.

Signed…………………………… Date…………………….

Kaarin J. Anstey (Principal supervisor)

Arranged the secondments, and contributed to the design and editing of the manuscript. Provided final approval of the manuscript to be published. I certify that this statement of contribution is accurate and permission is given for Lily O'Donoughue Jenkins to include this paper in this thesis for examination towards the Doctor of Philosophy

Signed…………………………… Date…………………….

The use of secondments as a tool to increase knowledge translation

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Article history

Key points

- Secondments have received very little attention in the knowledge translation (KT) literature
- This study looks at a reciprocal secondment as an example of how secondments could be used as a tool to increase KT by developing individual capacity
- Recommendations based on the case studies provided include creating a formal link between government and research organisations, trialling different types of secondments, and having a detailed evaluation plan to measure the success of the secondment

Abstract

This paper discusses the use of secondments as a tool to increase knowledge translation between academics and policy makers by developing individual capacity. A case study is presented of a reciprocal secondment between a government department and a university. Enablers of knowledge translation included flexibility and support, a prior relationship between the two organisations, and a government culture that values use of research in policy making. Barriers included the lack of a planned approach with agreed outcomes, and a lack of evaluation at the end of the secondment. Recommendations for future secondments include establishing ongoing secondments between organisations; trialling different types of secondments; and having a detailed plan at the beginning of a secondment, including how the success of the secondment will be measured, and a formal evaluation at the end.

Introduction

Knowledge translation (KT) is defined by the Canadian Institute of Health Research as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products, and strengthen the healthcare system.[1] There are three models of KT: the 'push' model emphasises researchers producing and communicating information to potential users[2]; the 'pull' model stresses user-driven research[3]; and the 'exchange' model emphasises human interaction, with researchers and knowledge users coproducing research and disseminating results.[1,3]

One of the most widely cited barriers to, and enablers of, KT is the relationship between researchers and policy makers.[4] To ensure evidence based policy, the interface between research and policy needs to improve. Actively building and maintaining relationships through discussions, meetings or workshops can lead to policy makers contributing to the research process and can increase the likelihood that research findings will inform policy decisions.[5] One approach to increasing the interaction or improving the interface between researchers and policy makers is use of secondments.[6,7,8]

Secondments have been used in the healthcare setting as a way to bring an individual's expertise to a team, and to develop staff knowledge and skills.[9,10] In the KT literature, secondments have received very little

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attention. Most of the initiatives used to develop KT research and activity involve courses and educational resources. However, in the experiential learning model, secondments, mentoring and collaborative projects are used to build KT capacity.[5]

Previous research has found that secondments involving researchers and healthcare practitioners are an efficient way to transfer research.[11] They give practitioners an opportunity to develop knowledge of research processes, and enable researchers to gain a better understanding of what research is relevant to practitioners and how to communicate their findings.[7,12] Secondments can benefit all parties at a relatively low cost.[12,13] The secondee has a chance to develop expertise in a specific area, and the host organisation receives some assistance and an external perspective on its projects. The seconding organisation also benefits from skills acquired during the secondment that can be applied to the secondee's substantive position and spread across the organisation to improve the skills of other staff.[9,12,14]

Although secondments occur between government departments and academic institutions, there has been minimal research on how they may contribute to increasing KT.[12] The aim of this paper is to discuss how secondments could be used to instigate and maintain relationships between government departments and universities, and how they could be an effective tool for KT by building individual capacity. This paper shares the experience of two example secondments; discusses the enablers of, and barriers to, these secondments; and provides recommendations for the future.

Reciprocal secondment

The reciprocal secondment occurred between the Australian National University (ANU) and the Australian Capital Territory (ACT) Health Department (ACT Health). A university researcher (the lead author) spent 10 months part time in a section of ACT Health. The researcher worked on a number of reports and projects within the department, but the secondment did not have a predetermined aim to produce a specific output. A staff member from ACT Health spent approximately 30 working days at the ANU centre that the researcher is from, during a period of 6 months. The secondment to the ANU had a specific project: to prepare a report using a dataset developed by the ANU centre.

Both secondees answered 10 open-ended questions in paper form, developed by the authors, about their experience of the secondment. The questions focused on four main topics: the experience of undertaking the secondment; enablers of, and barriers to, the success of the secondment; the perceived degree of success, and the basis on which these judgements were made; and secondments as a tool for KT.

Discussion

Secondment experience

Both secondees found that the secondment was a useful tool for KT, and that it strengthened the relationship between ACT Health and the ANU centre. They found that collaboration between the two organisations increased, and relevant knowledge and skills were exchanged. Through the secondment, the researcher learnt about current policy priorities and real-world constraints, how evidence was accessed and used in ACT Health, and the differences in writing style and use of language between researchers and government employees. This was important for the researcher in gaining a better understanding of how to communicate research findings.

The staff member from ACT Health believed that one of the benefits of the secondment was becoming more aware of academic resources. She found that a high level of support and communication during the secondment from senior staff at both organisations contributed to the success of the project; the two organisations worked collaboratively to develop and refine the project's aim, and the project output was delivered in a timely and high-quality fashion. The secondee recognised how secondments could be used to strengthen KT, stating that:

Secondments enable staff from both organisations to walk in the shoes of the other and thus promote better understanding of how each one approaches and uses knowledge in the context of their own organisation. Through this process, both organisations learn to share information in a manner that better ensures that the information can be used and understood in a meaningful and relevant way.

Barriers and enablers

The secondees differed in the amount of time spent at their host organisation and in the work they completed during their secondments. During the secondments, the participants undertook two roles concurrently and managed two workloads. In Gerrish and Piercy's study[9], secondees experienced difficulties in ensuring that sufficient priority was given to both roles. In our study, the secondments were flexible, so the secondees' usual workloads and the amount of time spent at either organisation could be adjusted. Previous research has found that flexibility is important to the success of secondments[15], so it was beneficial that both organisations supported these adjustments.

In relation to evaluating the success of the secondments, the secondment to the ANU was easier to evaluate because there was a specific output. This output was produced collaboratively, and generated research that ACT Health used to inform current policies

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and programs. By working on a range of projects, the secondee to ACT Health learnt more about government processes and created more links within the organisation. Neither secondment had an agreed evaluation plan before commencement.

Consistent with previous studies[3,9,12,14], the reciprocal secondment benefited both organisations and increased the secondees' capacity in relevant skills that could facilitate KT.[13,15 17] The ACT Health staff member increased her knowledge of current research, and developed skills in statistical analyses, and writing and publication of research. The researcher learnt more about the process of policy making, and the structure and culture of the government organisation, including issues facing the organisation. Although secondments develop an individual's capacity, this knowledge can also be translated to the organisation level and maximise KT efforts.[17] For example, when academic colleagues wanted to discuss their research with staff in ACT Health, the researcher was able to give the information to the appropriate person in the department.

Some aspects facilitated these secondments. Firstly, both secondees were familiar with the seconded organisation through previous experience. As Newman et al.[16] found, this provides some foundation for the relationship because both parties already have some cultural understanding of, and respect for, the other. Secondly, the current senior leaders in ACT Health are advocating for more research development from staff, including publishing of journal articles and collaboration with academics. This allowed the secondment process to proceed easily and efficiently.

Recommendations for the future

The first recommendation is concerned with maintaining and building the relationship in future. To prevent decreases in communication between the two organisations and to maintain momentum, Black and Martyn[13] suggest that a formal, even contractual, link be developed. One way of doing this is creating a partnership between the organisations through regular, perhaps annual, secondments. Secondments could occur between different departments and across all staff levels. A formal link may help to ensure that opportunities for interaction between the two organisations are maintained in the long term.[18] These collaborations could produce culture shifts, creating a decision-relevant culture among researchers, and a research-attuned culture among decision makers.[2]

The second recommendation is to trial different types of secondments to see which is more successful for KT. For example, organisations could consider short-term secondments with highly focused and defined objectives, or long-term, ongoing secondments. The success of the secondment type depends on the department, the project in question and the people involved. For example, Gerrish and Piercy[9] found that clinical secondees

benefited from ongoing clinical engagement through part-time secondments, but that academic secondees had difficulties managing dual workloads and benefited more from a full-time secondment.

Thirdly, it is recommended that secondments have a detailed plan before commencement and a formal evaluation of how successful the secondment was. For example, in Black and Martyn's secondment[13], they established a broad agreement covering basic contractual details, accountability, expenses and regular reviews. An evaluation at the end of the secondment could provide evidence of whether the secondment was effective in meeting outcomes, whether it met key objectives, what was gained by doing the secondment and any changes required for future secondments.[10]

Few projects have evaluated and documented the outcomes of KT processes. This may be because of difficulties defining, and thus measuring, a successful outcome.[8] One way to evaluate the outcomes of a secondment is to look at changes in practice or policy – for example, incorporation of relevant research into a policy. A second is to look at changes in understanding – for example, through increased knowledge, and changes in attitude and thinking. Finally, the processes used for KT can be evaluated, including how KT was conducted (e.g. formal arrangements, leadership, communication) and the quality of the processes (e.g. quality of information, cost-effectiveness).[19]

Conclusion

By examining two cases, this paper shows that secondments can increase KT between researchers and government departments by developing individual capacity. Barriers to the secondments included the lack of a planned approach with agreed outcomes and a lack of evaluation. Enablers included support and flexibility from both organisations, an existing relationship between the organisations, and a government culture that valued the use of research in decision making. Future research and monitoring are required to demonstrate the long-term outcomes of secondments, including for organisations. These outcomes may include a stronger relationship between the organisations, an increase in shared projects, and increased use of research in the policy process.

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Competing interests

None declared

Author contributions

LOJ was responsible for collecting data, and for designing, writing and editing the manuscript. KA arranged the secondment, and contributed to the design and editing of the manuscript.

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4.7 Breaking Down Barriers and Increasing Use of Research

Recommendations to both policy makers and researchers are provided in this section. These are actionable recommendations which could help to overcome the barriers of knowledge translation and increase the use of research in the policy making process.

The first recommendation is that a cross-representational committee similar to a board, that includes policy makers, researchers, clinicians and consumers, could be established to develop government-funded or donor-funded research that is relevant to policy and will be used by policy makers (Hyder et al., 2011). This would overcome issues of lack of funding for policy-relevant research that has clinical relevance. Researchers have also suggested that having a separate KT fund purposely for dissemination of research findings, being able to allocate more money to KT in their grant proposals, or having a flexible "slush fund" within the budget for KT would make it easier for them to do KT (Shantz, 2012).

With regards to time constraints there are two issues to overcome: 1) the amount of time it takes to produce quality scientific research may be too long for policy makers, and 2) it takes policy makers too long to locate and synthesise academic research which is relevant to current policy needs. Paper 1 identified that one way to overcome these issues is by developing new channels and ways of conducting business to share existing evidence. It recommended that scientists with specific expertise be invited into a particular department for a "scientific chat" to openly discuss planned policies. This would be particularly useful when commissioning new research would take too long but where there is substantial "soft" evidence already available to support the policy. To overcome the second issue, researchers should also be trained in how to produce and effectively communicate policy-relevant research in a format that is easily used by policy makers. For example, in one study the 1:3:25 report format developed by Canadian Health Services Research Foundation (2010) was supported by 100% of managers and 90% of policy makers interviewed (Lavis et al., 2005). Policy makers have indicated that summaries and syntheses of research are potentially useful to improving

the use of and access to relevant research. However, little is known about how policy makers use summaries in their work and so more information is needed to identify what content and format is most useful (Moore, Redman, Haines, & Todd, 2011).

Both government bodies and academic researchers need to ensure that policy makers have physical access to evidence. Government departments could achieve this by having subscriptions to relevant peer-reviewed journals or promote subscriptions to review material by organisations (e.g. Australian Healthcare and Hospitals Association, Sax Institute and Lowitja Institute) or by hiring a knowledge broker or expert. Researchers could disseminate their research findings in open-access journals or in non-traditional formats (e.g. in a 1:3:25 report format, via social media or in evidence summaries) or involve policy makers in the research process from the outset (McWilliam et al., 2009). Involving policy makers early in the research process might result in research questions being more relevant to current policy priorities and identification of gaps in the evidence or where available evidence could contribute to the policy process. Dissemination of research findings should contain useful content and be formatted so that policy makers can easily extract key information (Gagliardi, Berta, Kothari, Boyko, & Urquhart, 2016; Hyder et al., 2011; Moore et al., 2011). Policy makers also need to be encouraged to engage researchers early in a project.

Another way to increase the use of evidence in the decision-making process is by increasing the individual skills of both policy makers and researchers. Training should be provided to researchers on how to effectively communicate their findings (Brownson et al., 2006) and policy makers should be provided with the opportunity to learn how to access, understand and critically appraise research (Moore et al., 2011). Individual skills could be increased using strategies such as workshops, technical briefings, short courses or even secondments (Hyder et al., 2011). It is important that organisational capacity to use research also needs to be improved. An organisation's technical capacity and culture can affect employees' work performance as well as the adoption and adherence to superlative and innovative work practices (Makkar et al., 2016). Strategies to increase

organisational capacity may include developing an organisational culture that values the use of research and expects research to be used; using research experts and knowledge brokers to link policy makers and researchers; formulating research questions; committing time and resources to undertake research projects and increase research skills; and investing in systems and processes that support the access and use of research (Makkar et al., 2016; Moore et al., 2011).

To overcome the difference between researchers and policy makers both parties need to gain an understanding of what motivates the other and have consideration for the difference in rewards and recognition (McWilliam et al., 2009). As discussed above, researchers need to better communicate their research findings to policy makers. To make it easier for policy makers, researchers could include summaries with policy recommendations in their research (Innvaer et al., 2002). They should also tailor their language and statistical data to make it usable by policy makers (Haynes et al., 2011). If funding agencies made KT a mandatory requirement for projects then researchers may be encouraged to do KT (Shantz, 2012).

Predictors of KT success include researchers and policy makers having a pre-existing relationship, team communication and mechanisms for peer connection (McWilliam et al., 2009). Establishing an interface between researchers and policy makers may result in shared knowledge, greater understanding and improved communication. This could facilitate the use of evidence by creating trust and a shared vision that enables a more effective and sustained partnership. From this interaction researchers may gain an understanding of the policy or practice environment; become aware of policy makers concerns and windows; develop and pursue research questions that have real-world applicability; interpret results with a deeper understanding of contextual circumstances which may enhance the usefulness of the research findings; and be actively involved in the interchanges between evidence and policy (Brownson et al., 2006; Gagliardi et al., 2016). Interaction with researchers may enhance policy makers' knowledge and skills; become involved in the research process and gain information about other research; and create new contacts with other researchers

or policy makers (Brownson et al., 2006; Gagliardi et al., 2016). Black (2001) argues that if research findings are to have any impact than a closer relation between the two groups needs to be sustained during the research and beyond. Extensive interaction will further develop researchers understanding of the policy cycle and policy makers understanding of the research process (Shantz, 2012).

One way to bridge the gap between researchers and policy makers, to establish a relationship and promote knowledge exchange, is via the involvement of knowledge brokers. Knowledge brokers are individuals or organisations (such as the Sax institute) that attempt to develop a mutual understanding of policy makers and researchers' goals and cultures, identify where research is needed and create networks of people who share common interests (Dwan & McInnes, 2013). Some studies have identified that the use of knowledge brokers is potentially effective in linking research and policy communities (Moore et al., 2011).

The evidence from earlier in this chapter highlighted that the biggest barrier and enabler to KT is the relationship between researchers and policy makers. To increase the amount of research used in policy the most efficient recommendation is to improve, or even instigate, the interface between researchers and policy makers. This could be through formal processes, such as internships or secondments (McWilliam et al., 2009), collaborative research projects and knowledge brokers (Moore et al., 2011), or via informal processes, such as facilitating networks between the two groups, holding informal chats or workshops or by means of existing relationships. Having a dynamic interaction between researchers and policy makers has been cited as an ideal way to address complex health care problems as individuals with different expertise and perspectives can work together to formulate, implement and evaluate solutions (Gagliardi et al., 2016).

4.8 Summary

This chapter began by providing a definition of health policy and the policy cycle, including how research can contribute to each stage in policy formation. The chapter then went on to a manuscript about the use and evaluation of evidence by policy makers from different organisations compared to epidemiologists. It is recognised that a range of evidence and other competing interests inform policy decisions. The manuscript provided in this chapter discussed these competing interests and the preferred evidence of policy makers (systematic reviews). It also highlighted that there are similarities between academic epidemiologists and policy makers, such as not using grading hierarchies to evaluate evidence. However, there were also differences between the two groups, with epidemiologists more concerned with the rigour of methodology used in observational research and policy makers more concerned with what is accessible or has been shown to work. This chapter then briefly described six frameworks of KT and provided a detailed discussion of the WHO Ageing and Health KT framework, with an example of how it is currently being applied to the local context. The chapter then went on to provide more information on the KT process with a discussion on the barriers and enablers of KT. This chapter finished with our second paper on how secondments could be used as an effective tool to strengthen the relationship between researchers and policy makers and increase the use of research in policy.

The evidence from the current and previous chapter highlighted that the major barrier and enabler to KT is the relationship between researchers and policy makers. Both manuscripts in this chapter provided recommendations on how to increase the interface between researchers and policy makers and the uptake of research in policy making.

This is the last chapter of part two. Part three of this thesis goes on to discuss how research on health care service use and its association with cognitive impairment may have policy implications. The first chapter of part three, Chapter 5, discusses general practitioner use in individuals with mild cognitive disorder.

PART 3.

Chapter 5: GENERAL PRACTITIONER USE AND COGNITIVE IMPAIRMENT

5.1 Introduction

The previous part of this thesis (Part 2) provided an in-depth discussion of knowledge translation, including its frameworks and the barriers and enablers of linking producers and users of evidence. This part of the thesis discusses research findings on general practitioner (GP), emergency department and hospital use and their association with cognitive impairment (Chapters 5 to 7). The implications of these research findings for policy and practice are discussed in Chapter 8.

Consulting a GP is the second most common health-related action taken by Australians, after medication use (Australian Institute of Health and Welfare, 2004). Knowing the level and reason for use of GPs in Australia is important as there is increasing policy focus on the sustainability of healthcare costs in the context of population ageing and better patient care pathways (Pymont & Butterworth, 2015). In 2005 to 2006 the average number of GP visits was 8.6 per person for older Australians compared with approximately 4.0 per person for people aged under 65 (Australian Institute of Health and Welfare, 2007). People who had 20 or more visits to their GP per year were more than 16 times as likely to be aged 75 years and over compared to those who only had 1 to 3 visits (32% compared to 2%) (National Health Performance Authority, 2015).

Consultations with GP in the older cohort are increasing as the population ages. The findings from the BEACH study demonstrated that the proportion of GP encounters with people aged over 65 years increased from 26.5% in 2004 to 32.5% in 2013. When extrapolated, this increase means that in 2013 to 14 there were 17.3 million more encounters with older patients nationally than a decade earlier (Britt et al., 2014). Consultations with GPs are also becoming increasingly complex as the population ages and prevalence of co-morbidity increases (Britt et al., 2014).

5.2 Paper 3: A longitudinal analysis of general practitioner service use by patients with mild cognitive disorders in Australia

There have been a number of studies which have examined the prevalence of dementia in people accessing GP services (Albert et al., 2002; Eaker et al., 2002; Geldmacher et al., 2013a; Richards et al., 2000; Taylor & Sloan, 2000b; Zhao et al., 2008). However, the following article is the first to analyse the use of GP services by people with any Mild Cognitive Disorder (MCD) in Australia over eight years. To the authors knowledge it is also the first paper to analyse GP use of MCD participants when they have either a physical or mental comorbid condition, depression or arthritis. We chose arthritis and depression as our two comorbid conditions as both are highly prevalent in the elderly population, they are associated with increased disability and they are frequently managed in GP clinics. Finally, this article is the first to evaluate the effect of financial problems and access to social networks on the use of GP services by people with MCD.

Statement of authorship

A longitudinal analysis of general practitioner service use by patients with mild cognitive disorders in Australia. (2016). *Dementia and Geriatric Cognitive Disorders, 41*:324-333. doi: 10.1159/000447123.

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Lily O'Donoughue Jenkins (PhD candidate)

Developed study concept and design; analysed and interpreted data; drafted and edited the manuscript; acted as corresponding author. I certify that the statement of contribution is accurate

Signed…………………………… Date…………………….

Peter Butterworth (Co-author)

Drafted and provided critical revision of the article; assisted in interpretation of data analysis. Provided final approval of the manuscript to be published. I certify that this statement of contribution is accurate and permission is given for Lily O'Donoughue Jenkins to include this paper in this thesis for examination towards the Doctor of Philosophy

Signed…………………………… Date…………………….

Kaarin J. Anstey (Principal supervisor)

Assisted in developing the study concept and design; drafted and provided critical revision of the article; assisted in interpretation of data analysis; provided final approval of the manuscript to be published. Anstey is Principal Investigator on the PATH Through Life Study. I certify that this statement of contribution is accurate and permission is given for Lily O'Donoughue Jenkins to include this paper in this thesis for examination towards the Doctor of Philosophy

Signed…………………………… Date…………………….

Original Research Article

A Longitudinal Analysis of General Practitioner Service Use by Patients with Mild Cognitive Disorders in Australia

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Key Words
Health services research · Cognitive impairment · Comorbidity

Abstract
Background: The aim of this study was to ascertain if participants diagnosed with any mild cognitive disorder (MCD) visited a general practitioner (GP) more than those without MCD and the effect of either depression or arthritis on GP use longitudinally. *Methods:* 2,551 participants aged 60–64 years at baseline completed the Personality and Total Health Through Life (PATH) study in Canberra. Follow-up data were collected after 4 and 8 years. A cognitive screening battery was used to screen participants into a substudy of MCD. *Results:* Participants with any MCD had greater GP use than cognitively healthy participants across all three waves (wave 1, M = 7.35 vs. 5.59; wave 2, M = 7.77 vs. 5.86; wave 3, M = 9.01 vs. 6.81). After adjusting for demographic and health factors, MCD was a significant predictor of GP use at all three waves (p < 0.05, CI 0.84–0.99). *Conclusion:* This study has shown that MCD is associated with a higher use of GP visits, especially if the patient has a comorbid condition.

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Introduction

It is estimated that 22% of the US population aged 71 years or older have a mild cognitive disorder (MCD) [1]. In most clinic-based studies, 40–80% of patients with MCD progressed to dementia during a 5-year follow-up period. The average annual conversion rate for MCD to dementia is 10–15% over 1 year [2], increasing to 19–66% over 3–5 years [3]. In the cognitively healthy older population, conversion to dementia is estimated to be only 1–2.5% per

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year [1]. Hence, a larger proportion of the older population has MCD than dementia. Although most individuals with any MCD are able to live independently [4], they may have significantly more difficulty with daily activities [5, 6]. Older adults with any MCD have more comorbid medical conditions, such as stroke, hypertension, diabetes mellitus [7–9] and cerebrovascular disease, than those without any MCD [10]. Mood disorders, such as anxiety or depression, have also been found to be more prevalent in people with cognitive impairment [8, 11–13]. To prolong living within the community, individuals with cognitive or physical impairments may utilise more health services [5], particularly primary care.

This study examines general practitioner (GP) use by people with any MCD in Australia as GPs are the most commonly used primary care service [14]. Adults aged 65 years and older comprise the fastest growing segment of the population. This may result in an increase of patients with MCD, increasing the burden on the healthcare system [15]. This burden is not only economic but may also strain the overall availability of health services; GPs may spend an increasing amount of time with older patients and likely more so with individuals with any MCD. It is therefore important that research be conducted about the potential impact of cognitive impairment on GP services. Such research is required to enable the development of strategies to meet the increased need for services and ensure that services are appropriate for these patients [5].

There has been little research which has compared the GP use of MCD individuals with the GP use of those individuals with a physical or mental condition, commonly presented in GP consultations, and how these conditions may affect GP use in MCD individuals over time. Previous studies have found that income and social support are associated with health service use [16, 17], especially in patients with dementia [18]. However, to the authors' knowledge, no studies have evaluated the effect of financial problems and social network on MCD individuals' use of GP services. In this study, it is expected that experiencing financial problems and having a large social network would increase the use of GP services.

Results from the sparse research on GP visits and MCD are varied. Several studies have found that individuals with any MCD visited their GP, or used health services, significantly more than those with no cognitive impairment [7, 10, 19]. The annual cost of these services was substantially higher for MCD patients than for those without [10, 20]. Other research has found that, compared to controls, the frequency of GP contact increased in the 2–5 years prior to dementia diagnosis [9, 20]. The cost and use of healthcare services was noticeably higher in the year prior to dementia diagnosis compared to controls [9, 12]. The total medical cost over 1 year was USD 5,549 more for prediagnosed Alzheimer's disease patients than controls [12], and Alzheimer's disease patients had an average of 6.6 GP visits whereas controls had 3.8 [9]. Other research has found no association between cognitive decline and contact with a GP [5, 19, 21]. Finally, there is research which shows that cognitive impairment is associated with fewer visits to GPs [17].

Previous research has found that multimorbidities are associated with significantly more GP visits in older adults [22, 23]. The aim of the present study was to evaluate the number of GP visits by individuals with any MCD compared to those without cognitive disorders, and investigate whether the presence of one comorbid condition, physical or mental, would increase GP use. Arthritis provides comparison to a physical condition, whereas depression is used as comparison for another mental condition. Arthritis and depression were chosen due to their high prevalence, their association with disability, and because both conditions are frequently managed in GP services [14, 24]. For example, arthritis was the most common physical condition among Australian adults in 2011–2012, affecting 14.8% of the Australian population, and contributed to 3.8% of all GP visits. Depression was the most common mental condition, affecting 9.7% of the population, and contributed to 4.1% of all GP visits [14]. Furthermore, cognitive impairment has been associated with these conditions in previous

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studies [25, 26]. We hypothesised that participants with any MCD would have higher rates of GP consultations than those of the same age without any MCD. Furthermore, we hypothesised that the presence of any MCD would increase service use amongst those with comorbid conditions, such as arthritis and depression.

Methods

Participants

The Personality and Total Health Through Life (PATH) Study, and the clinical Health and Memory Substudy, surveys participants from three cohorts, 20–24, 40–44 and 60–64 years at baseline. Participants resided in Canberra and surrounding regions and were recruited through the electoral roll. Each cohort was interviewed, in turn, over a 1-year period and followed up every 4 years [for more information on the PATH study, see 27, 28]. This investigation focusses on the older cohort over three assessments, a total of 8 years of follow-up time with a mean follow-up of 4 years. At baseline, 2,551 participants completed the interview. Due to diagnosis of dementia, 1 participant each was excluded at wave 1 (n = 2,550) and wave 2 (n = 2,221). At wave 3, 8 participants were excluded (leaving a total of n = 1,965). Written informed consent was obtained from all participants prior to involvement in the study, and the Australian National University Human Research Ethics Committee approved the study.

GP visit data were sourced by linking consenting participants' data to their records from the Medicare Benefits Schedule (MBS). The MBS is a list of Medicare services subsidised by the Australian government, it includes the date of consultation and the type of service provided. The analysis considers the number of GP visits for the period of 6 months prior to and 6 months after the PATH interview; this approach has been used in previous research [29]. The measure was based on specific Medicare item codes, which account for the majority of GP visits.

Clinical Assessment

A cognitive battery was used to screen participants into a substudy on neurocognitive disorders including mild cognitive impairment (MCI) and dementia [30]. Participants were selected for clinical assessment if they had any of the following: (i) a Mini-Mental State Examination (MMSE) [31] score ≤25, (ii) a score below the fifth percentile score from wave 1 on immediate or delayed recall of the California Verbal Learning Test [32] (immediate or delayed score of <4 and <2, respectively), or (iii) a score below the fifth percentile on two or more of the following tests: Symbol Digit Modalities Test [33] (<33) or Purdue Pegboard with both hands [34] (wave 1, <8; wave 2, <7), or simple reaction time [35] (third set of 20 trials; wave 1, >310 ms; wave 2, >378 ms).

The clinical assessment involved a structured clinical assessment for dementia, a neuropsychological assessment, and the Clinical Dementia Rating Scale. Diagnoses were formulated from clinical checklists, data from the neuropsychological assessment, and neuropsychological and medical history [27, 36]. The classification of any MCD, which includes MCI, age-associated memory impairment, age-associated cognitive decline, mild neurocognitive disorder, and other cognitive disorders, has been found to be highly stable over a 4-year follow-up [28] and so this general classification was used. A description of the neuropsychological assessment and diagnostic criteria is included in the online supplementary material (see www.karger.com/doi/10.1159/000447123).

Of the 224 participants that met the criteria for the substudy at baseline, 107 refused to participate and 26 were found to be cognitively healthy. From the remaining participants, 84 were confirmed as having MCD, and 37 of these had MCI. The predicted prevalence of MCD in the entire sample was then calculated to correct for false negatives and attrition [37]. From this calculation, an additional 163 participants were identified with likely MCD, resulting in 247 participants classified as having any MCD at baseline. At wave 2, 2,222 participants completed the PATH interview (12.9% attrition). Of these participants, 155 were selected for the substudy, but only 138 agreed to participate and were diagnosed with MCD. Finally, at wave 3, 1,973 participants were interviewed for PATH (11.2% attrition); 181 met the criteria for the substudy, but only 166 were confirmed as having MCD. After calculating the prevalence, there were 217 MCD participants at wave 2, with 54 of these having MCI. At wave 3, there were 197 participants with estimated MCD, 97 participants having MCI. A flowchart of recruitment is shown in figure 1.

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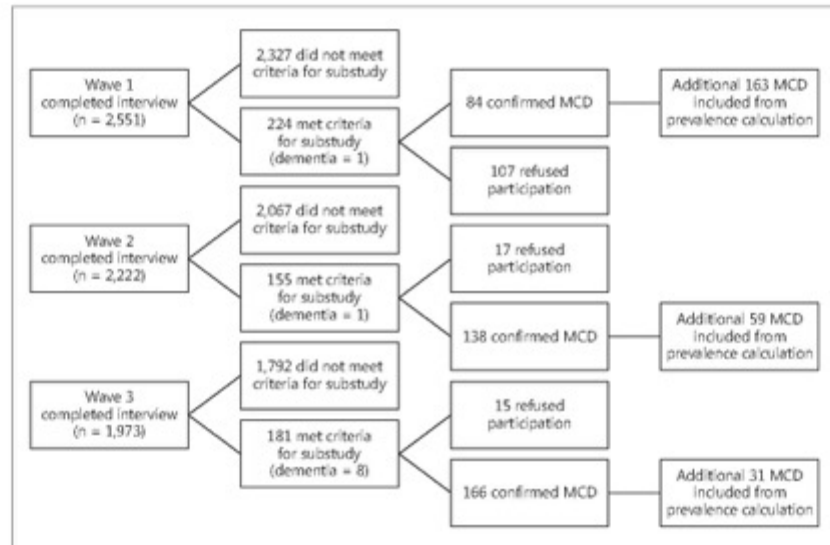
Fig. 1. Flowchart of recruitment for waves 1, 2 and 3.

Health and Income Measures

Depression was measured using the Brief Patient Health Questionnaire (BPHQ) [38]. Participants categorised with no or subsyndromal depression were classified as 'no depression'. Participants who scored in the minor and major depression categories were classified as 'depressed'. During the PATH interview, participants self-reported any history of arthritis, diabetes mellitus, stroke, and any heart problems, and whether they had experienced any financial problems. Their blood pressure was measured.

Social Measures

Participants' social network was measured using the abbreviated Lubben Social Network Scale (LSNS-6). In accordance with previous research [39], a cut-off point of 12 was used to categorise participants into 'at risk of social isolation' or 'not at risk'.

Statistical Analyses

Statistical analyses were performed using SPSS 20. To calculate the predicted prevalence of MCD in the cohort, predictive regression models were built based on the relationship between the screening measures and the clinical data for the subsample for which diagnostic data were available using methods described previously [37]. Using the clinical diagnoses as the gold standard, logistic regressions with age, sex, and screening measures as predictor variables were built. For each diagnostic criterion, a predictive score, defined as the probability of positive diagnosis, was derived and a cut-off point was chosen so that the number of predicted diagnoses was the same as the number of observed diagnoses under the criterion in the subsample. This cut-off point was then applied to the predictive score of those who screened positive but did not undertake the clinical assessment and those who screened negative. The final MCD sample was a sum of those who had received a clinical diagnosis, those estimated to receive a diagnosis among the group that screened positive but did not receive a diagnosis, and those estimated to have been falsely screened as negative [30].

Descriptive statistics and nonparametric t-test analyses were performed to see the difference between MCD participants and non-MCD participants' use of GPs at each wave. Participants were then further categorised into whether they had a comorbid condition of depression or arthritis. Participants who had MCD,

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Table 1. Descriptive statistics with estimated marginal means for each condition at baseline

	Participants, n	Mean GP use (SE)	Males, %	Married, %	Mean age, years (SD)	Mean education, years (SD)
MCD	247	8.19 (0.58)	59.1	70.4	62.53 (1.50)	11.73 (3.05)
Non-MCD	2,303	6.82 (0.30)	50.8	75.4	62.51 (1.51)	13.99 (2.68)
MCD and arthritis	92	9.24 (0.78)	49.1	62.9	62.51 (1.44)	11.16 (3.06)
MCD and depression	36	10.56 (0.81)	52.9	54.9	62.76 (1.46)	11.15 (3.22)

SE = Standard error.

arthritis, and depression were not included in the analyses due to small sample size. To test whether the groups significantly differed from each other, nonparametric t tests were performed.

Generalised estimating equations (GEE) were used to test whether MCD was significantly associated with GP use longitudinally. As the outcome variable, number of GP consultations, is a count variable and screening showed that it was overdispersed, negative binomial with log link function regression models were specified. A hierarchical approach was used to test the association of MCD and GP use. The first model was adjusted for gender, education, financial problems, married or not, and wave and included arthritis, depression, and MCD. In the second model, additional health variables were included to evaluate whether associations remained after adjusting for these. The third model evaluated whether participants' social network would affect their GP use. All tests were two-tailed.

Results

Descriptive statistics with estimated marginal means at baseline for participants with MCD and non-MCD are shown in table 1. Across all three waves, participants with MCD were more likely to be male and had lower levels of education than non-MCD participants.

Use of GP Services

MCD participants had a total of 4,440 GP visits across the three waves. At wave 1, 169 participants (6.6%), consisting of 154 non-MCD and 14 MCD participants, did not have a GP consultation 6 months prior to or after the PATH interview. The maximum number of consultations for MCD participants was 42 and the median was 6 consultations. At wave 2, 107 participants (4.2%), 97 non-MCD and 10 MCD participants, had no GP consultation. The maximum number of visits for MCD participants was 39 and the median was 5. By wave 3, only 93 participants (3.7%) had zero GP consultations, 91 non-MCD and 2 MCD participants. The maximum number of consultations for MCD participants was 45, with the median increasing to 7 visits.

MCD participants had significantly more GP visits than non-MCD at baseline [M = 7.22 (standard deviation, SD = 6.71) vs. 5.50 (SD = 4.78), U = 172,900.00, z = –3.65, p < 0.001]. As participants got older, the number of mean visits increased. At waves 2 and 3, MCD participants attended significantly more GP visits than non-MCD participants [wave 2, M = 7.13 (SD = 5.79) vs. 5.84 (SD = 4.81), U = 139133.50, z = –2.91, p = 0.004; wave 3, M = 9.12 (SD = 7.53) vs. 6.58 (SD = 5.27), U = 123125.50, z = –4.49, p < 0.001]. A retrospective power analysis on the initial baseline analysis suggested that our sample provided power of 0.52 to detect a difference of the observed magnitude at p < 0.05.

Participants with both MCD and arthritis had significantly more (p < 0.001) GP visits than non-MCD participants at every wave. There was a significant difference between GP use of participants with only MCD and GP use of participants with both MCD and arthritis at

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Fig. 2. Graph comparing the mean number of GP visits for participants with MCD, cognitively healthy participants (non-MCD), participants with both MCD and depression, and participants with both MCD and arthritis across the three time points.
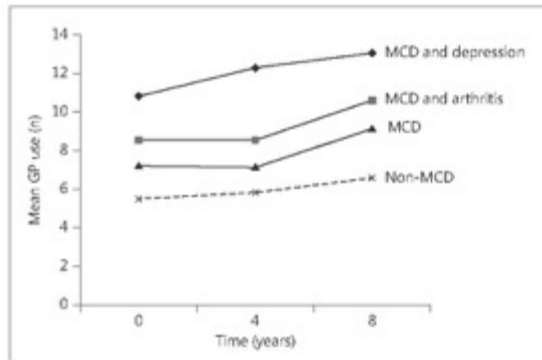
every wave (p < 0.001), participants with both arthritis and MCD having a higher mean GP use [wave 1, M = 8.52 (SD = 6.45) vs. 6.07 (SD = 6.75); wave 2, M = 8.55 (SD = 6.55) vs. 5.61 (SD = 4.50); wave 3, M = 10.6 (SD = 7.42) vs. 7.36 (SD = 7.31)]. There was also a significant difference across all three waves between participants with MCD (no arthritis) and participants with arthritis who were cognitively healthy (p < 0.05), participants with arthritis having slightly higher means than MCD participants [wave 1, M = 6.78 (SD = 5.68) vs. 6.07 (SD = 6.75); wave 2, M = 6.86 (SD = 5.19) vs. 5.61 (SD = 4.50); wave 3, M = 7.63 (SD = 5.62) vs. 7.36 (SD = 7.31)].

Participants with both MCD and depression used significantly more GP services than participants who had only MCD in all waves [p < 0.05; wave 1, M = 10.81 (SD = 9.32) vs. 6.45 (SD = 5.72); wave 2, M = 12.28 (SD = 8.88) vs. 6.59 (SD = 5.11); wave 3, M = 13.05 (SD = 9.34) vs. 8.64 (SD = 7.21)]. Participants who had depression but were cognitively healthy had significantly more GP visits than MCD participants (no depression) in waves 1 and 2 (p < 0.05) but not in wave 3. Participants who had both depression and MCD had the highest mean GP use, and this was significantly more than that of non-MCD participants at all three waves (p < 0.001). The mean use of GP visits for participants with MCD, non-MCD, MCD and depression, and MCD and arthritis across the three waves is shown in figure 2.

GP Use Adjusting for Demographic, Health and Social Variables Longitudinally

The first GEE analysis was a basic model which adjusted for gender, education, married or not, arthritis, depression, financial problems, wave and MCD. Gender, education, arthritis, depression, wave (p < 0.001), and MCD (p < 0.05) were all significantly associated with GP use. Participants with MCD had 12% more GP consultations than those without; this increased to 22% in those with arthritis and to 37% for depression. A number of interaction terms were also tested in this basic model, including MCD by depression, MCD by arthritis and MCD by wave. None of these interactions were significant.

The second GEE analysis controlled for the significant variables in the basic model as well as other health variables, including diabetes, high blood pressure, heart trouble and stroke. Gender, education, arthritis, depression, wave (p < 0.001), financial problems and MCD (p < 0.05) remained significant after controlling for these other health variables. Diabetes, high blood pressure, heart trouble and stroke were all significant (p < 0.001).

The third GEE analysis controlled for the variables in the basic and extended model as well as social isolation. Gender, education, arthritis, depression, high blood pressure, heart

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Table 2. Longitudinal GEE analysis: basic model, model 2 and model 3

Parameter	Basic model			Model 2			Model 3		
	β	Exp(B)	CI	β	Exp(B)	CI	β	Exp(B)	CI
Intercept	2.35**	10.49	8.55, 12.88	1.96**	7.08	5.30, 9.45	1.99**	7.32	5.38, 9.95
Gender (male)	−0.12**	0.89	0.84, 0.95	−0.15**	0.86	0.82, 0.91	−0.14**	0.87	0.82, 0.92
MCD	0.10*	0.91	0.84, 0.99	0.10*	0.91	0.84, 0.99	0.07	0.93	0.86, 1.02
Arthritis	0.19**	1.21	1.15, 1.27	0.18**	1.2	1.14, 1.26	0.17**	1.19	1.13, 1.25
Depression	0.30**	0.74	0.67, 0.82	0.28**	0.76	0.70, 0.84	0.28**	0.76	0.68, 0.84
Education	−0.02**	0.98	0.97, 0.99	−0.02**	0.98	0.97, 0.99	−0.02**	0.98	0.97, 0.99
Wave	0.10**	1.11	1.09, 1.13	0.09**	1.09	1.07, 1.12	0.09**	1.09	1.07, 1.12
Married	0.03	0.97	0.92, 1.03	0.02	0.99	0.93, 1.04	0.02	0.99	0.93, 1.05
Financial problems	0.12**	0.89	0.82, 0.96	0.09*	0.91	0.85, 0.98	0.10*	0.91	0.85, 0.98
Diabetes				0.20**	1.21	1.12, 1.31	0.19**	1.20	1.11, 1.31
High blood pressure				0.20**	1.21	1.15, 1.27	0.18**	1.20	1.14, 1.26
Heart				0.26**	1.30	1.22, 1.37	0.26**	1.30	1.22, 1.38
Stroke				0.34*	1.41	1.09, 1.82	0.32*	1.37	1.05, 1.80
Socially isolated							−0.02	0.98	0.90, 1.07

CI = Confidence interval. ** p < 0.001, * p < 0.05.

trouble, wave, diabetes (p < 0.001), stroke and financial problems (p < 0.05) remained significant after controlling for social isolation. MCD and social isolation were not significant in this model. The results of the GEE models are shown in table 2.

Discussion

The aim of the present study was to compare the number of GP visits by individuals with any MCD to those without cognitive disorders, and to investigate whether the presence of one comorbid condition, depression or arthritis, would increase GP use in participants with any MCD. As hypothesised, MCD participants used significantly more GP services than participants without MCD. MCD was also significantly associated with increased GP use longitudinally. Contrary to our hypothesis, results from nonparametric t tests showed that participants with arthritis, who were cognitively healthy, visited their GP significantly more than participants with only MCD across all three waves. Participants with depression used significantly more GP services than participants with only MCD in waves 1 and 2 only. As hypothesised, participants who had both depression and MCD had more GP visits overall. However, there was no interaction effect between depression and MCD, or arthritis and MCD, at any wave, suggesting that these variables are independent contributors and so it is not the presence of these comorbid conditions that leads to disproportionately higher levels of service use.

The findings of this study are consistent with previous research [7, 10, 20]. Participants with MCD are using GP services more than others of the same age who do not have a cognitive impairment. These findings provide us with some understanding of the characteristics of older GP patients. The association between MCD and GP use was significant after adjusting for other sociodemographic and health variables, arthritis and depression. However, this increased use may be partly explained by the presence of a comorbid condition. In our study, individuals with both MCD and depression had the highest number of GP consultations, followed by participants with MCD and arthritis.

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To our knowledge, this is the first paper to compare GP use of MCD participants with GP use of participants with arthritis or depression. One previous paper has investigated use of primary care services in elderly participants with depression compared to controls and found that participants with depression had two more appointments per annum on average than nondepressed participants [40]. This is similar to our finding that depression increases service use, especially as a comorbid condition of MCD. A study on rheumatoid arthritis patients found that they used GP services more frequently than rheumatologist services in the previous year (4.7 vs. 3.5 mean visits) [41]. Participants with arthritis in our study visited their GP more than this (mean from wave 1 to wave 3 = 6.8–7.63 visits), and this increased when the participant also had MCD (mean from wave 1 to wave 3 = 8.5–10.6 visits). This difference may be due to study design, but our findings demonstrated that the presence of MCD increased GP use in arthritic participants. Our results indicate that the presence of MCD with a comorbid condition is contributing to a high GP use. As the ageing population is increasing, and with this the rate of MCD, GP use is also expected to increase in the future.

People with MCD may utilise more GP services to seek help with symptoms of cognitive decline, but their higher usage may also be due to poorer management of comorbid conditions or having more accidents or injuries [12]. Previous research has hypothesised that the use of GPs may also be affected by participants' living arrangement, income or access to services [10, 17]. For example, individuals with MCD may rely on informal support rather than formal services [21]. We found that participants with MCD who experienced financial problems had significantly more GP visits. However, after adjusting for social network we found that MCD was no longer significant. However, the effect of social network did not reach significance, suggesting that the effect of social network was small or that attenuation was due to the number of variables in the model rather than social networks specifically.

Our study has some limitations. The Medicare data used only included a specific subset of GP consultations and did not include information on reason for GP visit. Despite our large sample size we had a relatively small number of MCD, which limited statistical power. Although retrospective power calculation is controversial [42, 43], consideration of the initial baseline analysis suggested that our sample provided a medium power effect of 0.52 to detect a significant difference.

Nevertheless, we did find significant results which may underestimate the impact of MCD on GP use because the sample is well-educated. A strength of our study is that participants were aged 60–64 years at baseline, which is to our knowledge the youngest sample of adults with MCD examined in relation to health service use. Most research on MCD is focussed on much older adults. Hence, our study reports what is to our knowledge unique data on the cognitive impairment in the working-aged population.

GP use among patients with MCD may be affected by collinearity with other conditions and treatment. For example, if individuals have both depression and MCD, then they may be visiting their GP for prescription medicine only, once their depression is managed then their cognition may improve and their GP use decrease. Use of services may be related to cognitive decline, or individuals may be using these services for conditions that are exacerbated by the presence of cognitive impairment. It is important that future research looks at how service use patterns relate to cognitive decline over time, and whether this use is affected by comorbid conditions. Such research could contribute to identifying predictors of decline, and to identify appropriate points along the disease course for interventions aimed at improving the management of MCD and comorbid conditions in the ageing population long term [44].

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Acknowledgments

Disclosure Statement

The authors declare that they have no competing interests.

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5.3 Summary

We found that individuals in Australia with MCD were visiting their GP significantly more than individuals who were classified as cognitively healthy. This usage significantly increased if MCD participants had a comorbid condition, arthritis or depression. This article highlights the increasing need for public health strategies to deal with the increased use of GPs in the future. The manuscript reflects, and confirms previous research findings of the increasing need for GPs by older individuals in the community. The importance of GPs for individuals with early signs of memory impairment is discussed in the literature review (Chapter 2).

Due to the increase in the ageing population and the corresponding rise in cognitive impairments, it is anticipated that there will be an increased need in future for GP or similar services. This may result in longer waiting times for patients, insufficient time spent with patients and care needs not being met. For example, in 2013 Canberra residents waited an average of 6.73 days to see their usual GP (Boddy, 2014). To overcome these prolonged waiting times individuals may present to an emergency department or visit a different GP who is not aware of the patient's history. The Australian government and GPs in ACT should develop new approaches to meet this increased need or change or modify services currently provided to ensure that they are appropriate for these patients (ACT Health Directorate, 2011; Comijs et al., 2005).

Paper 3 highlights the issue that individuals with a cognitive impairment are more likely to visit a GP if they have a comorbid condition (physical or mental). Use of services may be indirectly related to cognitive impairment, or individuals may be using these services for conditions that are exacerbated by the presence of cognitive impairment. For example, evidence has found that is more frequent in people with dementia and MCI compared to cognitively healthy individuals (Ellis et al., 2009; Shahnawaz et al., 2013). Depression has also been shown to contribute to impairment in several cognitive domains, including executive function, attention and psychomotor skills (Gonda et al., 2015) and low memory performance has been shown to be a reliable predictor of depression

three years later (Airaksinen, Wahlin, Forsell, & Larsson, 2007). The association between depression and mild cognitive disorders can be clinically challenging and cognitive dysfunction in depressed patients is largely unrecognised and unmonitored by clinicians (Gonda et al., 2015; McAllister-Williams et al., 2017). Further research examining the presence of comorbidities, such as depression, and effect on cognitive impairment is required, particularly regarding the nature and treatment of cognitive impairment.

In the process of conducting research for paper 3 a number of gaps were identified. MCI is an unstable condition - individuals may stabilise, revert back to normal cognition or progress to dementia. However, there has been little or no research examining the effect that changes in cognitive status over time have on health service use. Future research could use linked longitudinal data, such as that used in the article, to examine the multiple exposures, determinants and outcomes of cognitive status changes and GP use. Previous research has examined the impact of comorbid conditions on dementia and health service use, for example Griffith et al. (2016) and Browne et al. (2017). However, very little research has examined comorbid conditions in people with MCI/MCD. Given this gap, future research should examine whether particular comorbid conditions are associated with MCI/MCD or lead to increased service use. Previous research has largely focused on individuals from a clinical sample. Future research examining the association between MCI/MCD and primary care should focus on community-dwelling individuals as they tend to have more medical problems and their cognitive impairment is rarely identified (Fowler, 2013). Results in paper 3 indicate that increased health service use can be used as a proxy for health costs with even mild cognitive disorders. Future research which examines the reason for increase will enable the development of appropriate public health policy.

Research findings discussed in this chapter highlight the importance of examining the impact of cognitive impairment on GP use. However, the impact of cognitive impairment on hospital services

appears to be relatively greater than that on GPs (Australian Institute of Health and Welfare, 2004).

The next chapter discusses the relationship between cognitive impairment and hospital use.

Chapter 6: HOSPITAL USE AND COGNITIVE IMPAIRMENT

6.1 Introduction

The previous chapter highlighted that GPs are an extremely important service for older people, especially for the diagnosis and management of cognitive impairments, including dementia. In paper 3 the authors found that the presence of MCD increased visits to a GP over a long period of time. This chapter follows with a discussion on the association between hospital use and cognitive impairment.

People aged 65 years and older use a high amount of hospital services. In 2014-2015 they accounted for 41% of hospital admissions, 48% of patient days and 20% of all emergency department presentations (Australian Institute of Health and Welfare, 2017). Hospitalisation for older people has also increased by an average of 6% each year between 2011-12 and 2015-16, even though the population growth for this age group was only about 4.3% over the same period (Australian Institute of Health and Welfare, 2017). Individuals with dementia have hospitalisation rates 1.5 to 3 times higher than people with other chronic conditions (Bass et al., 2015). Given hospital use is relatively high in older age groups, and the risk of dementia as people age, hospital staff can expect that the number of elderly people presenting with memory problems in addition to medical and/or surgical problems will increase with the ageing population (Galvin et al., 2010). This will present a significant challenge for the management, supply and demand of hospital services (Australian Institute of Health and Welfare, 2007).

As discussed in the literature review (Chapter 2) there is an association between cognitive impairment and hospitalisation, with hospitalisation increasing the risk of cognitive impairment, and cognitive impairment being a risk factor for increased hospitalisation. Use of hospitals is often due to complications in coexisting conditions that are caused by dementia and individuals with dementia have more preventable hospitalisations and ED visits, mostly due to poor post-discharge and

transitional care (Bass et al., 2015; Bynum et al., 2004; Callahan et al., 2012; Wolinsky et al., 2008).

Hospital use also has unintended negative consequences for individuals with dementia. Family

members often identify that after a hospital admission levels of cognitive functioning do not return

to their preadmission levels (Bass et al., 2015).

6.2 Paper 4: Longitudinal analysis of cognitive decline with hospitalisation over 12 years of follow-up in the PATH Through Life Study

Much of the previous research on hospitalisation and cognitive impairment has looked at the

prevalence of cognitive impairment and dementia in hospitalised patients and decline of cognition

after surgery (Canet et al., 2003; Monk et al., 2008; Newman et al., 2001), critical hospitalisation and

treatment in intensive care units (Hopkins & Jackson, 2006; Pandharipande et al., 2013; Torgersen,

Hole, Kvåle, Wentzel-Larsen, & Flaatten, 2011; Wolters et al., 2013) and after non-critical

hospitalisations (Ehlenbach et al., 2010; Wilson et al., 2012).

There are several limitations with previous research that has examined the impact of

hospitalisation on cognition. Firstly, there are very few long-term follow-up studies based in

Australia which examine the association between hospital use and cognitive impairment. Secondly,

most of the previous studies use retrospective measurement of cognition before hospitalisation.

Thirdly, the cognitive measurements differ between studies, making comparison difficult. Some of

the previous research has used a screening tool, for example the Telephone Interview for Cognitive

Status (Davydow et al., 2013), Cognitive Abilities Screening Instrument (Ehlenbach et al., 2010),

MMSE (Chen et al., 2011; Gruber‑Baldini et al., 2003; Helvik et al., 2012; Torgersen et al., 2011) or

the modified Mini-Mental State (Shah et al., 2013) to categorise impairment. Other research has

used a neuropsychological battery with varying cognitive tests. In previous research the results from

these cognitive tests have been formed into a composite (Canet et al., 2003; Monk et al., 2008;

Wilson et al., 2012), have used raw scores (Woods et al., 2011) or done a factor analysis (Newman et al., 2001). Fourthly, performance in cognitive tests may be sensitive to the environment in which they have been administered. For example, cognitive tests that have been administered multiple times in hospital may have been biased by practice effects or the mood of the patient at the time.

Previous studies also differ in the intervals between cognitive assessments. For example, Chen et al. (2011) compared cognitive status at admission, before discharge, at 3 months and finally at 6 months after discharge. Other studies compare cognition from one year after hospitalisation (Gruber‑Baldini et al., 2003; Helvik et al., 2012) to up to 5 years (Newman et al., 2001). Fifthly, studies differ in the factors they control for, such as medication use, receiving anaesthetic, presence of delirium and cognitive status prior to hospitalisation. Finally, participants in previous research may not be representative of the sample. Participants suspicious, or aware, of some decline in cognition may have elected not to partake in the study and participants who are healthy may be overrepresented.

The following paper (paper 4) attempts to address some of the limitations of the previous research. Firstly, the study is based on a large sample of Australians with follow-up data from 4 waves, over 12 years with small attrition rates. The paper examines both directions of the relationship between hospitalisation and cognitive impairment- whether a hospital visit is associated with a decline in cognitive ability and whether cognitive impairment results in longer hospital stays or more hospital admissions.

Secondly, the study is based a prospective cohort design. Cognition for the entire sample was measured at baseline for all participants and again at the three different time points. The number and duration of hospitalisations of participants in the sample were obtained from medical records, not from prospective self-report, and matched to each participant across time points, including for those with no hospitalisations between each wave.

Thirdly, most of the previous studies rely on a screening instrument (Davydow et al., 2013; Ehlenbach et al., 2010; Weiler et al., 1991)or a composite cognitive score (Canet et al., 2003; Monk et al., 2008; Wilson et al., 2012). By using only one instrument to measure cognition, results may not be testing the full spectrum of cognition and composite scores may have methodological problems such as lack of reliability or lack of sensitivity to domain specific effects. For example, memory or processing speed may be affected by hospitalisation but this effect could be diluted in a composite of measures that are not affected by hospitalisation.

In the present study the authors have used a range of separate cognitive tests to measure cognitive impairment, including the MMSE, the CVLT, digit span backwards, spot-the-word test and the SDMT, and thus have a better representation of cognitive function. By using this range of instruments, including the MMSE, we can compare the results of this study to some of the previous research. The cognitive tests used in this study have been administered in a controlled environment and have demonstrated high reliability and validity so any significant changes within this sample are indicative of changes in cognition.

Finally, unlike previous studies which focus on following-up patients who have been hospitalised (Davydow et al., 2013; Helvik et al., 2012; Newman et al., 2001), participants in our study were community-dwelling individuals who were randomly selected from the electoral roll. Participants' cognitive status was measured at baseline and any participants with dementia or MCD were excluded. Rather than examining cognitive impairment in individuals who have been hospitalised versus not hospitalised this paper investigates cognitive impairment between individuals with none, one or multiple hospitalisations.

Statement of authorship

Longitudinal analysis of cognitive impairment with hospitalisation over 12 years of follow-up in the PATH Through Life Study. *Under review*

Lily O'Donoughue Jenkins (PhD candidate)

Developed study concept and design; initiated data linkage process with CHeReL; submitted ethics approval and project proposal for linkage of ACT Admitted Patient Care data and PATH data to CHeReL; prepared spreadsheet with hospital data provided by CHeReL, health and sociodemographic variables extracted from PATH; analysed and interpreted data; drafted and edited the manuscript; acted as corresponding author. I certify that the statement of contribution is accurate

Signed…………………………… Date…………………….

Kaarin J. Anstey (Principal supervisor)

Assisted in developing the study concept and design; drafted and provided critical revision of the article; assisted in interpretation of data analysis; provided final approval of the manuscript to be published. Anstey is the lead investigator of the PATH Through Life Project and has obtained funding and overseen data collection since 2007. I certify that this statement of contribution is accurate and permission is given for Lily O'Donoughue Jenkins to include this paper in this thesis for examination towards the Doctor of Philosophy

Signed…………………………… Date…………………….

Cognitive decline and hospitalization

ABSTRACT

Background: A number of studies have examined the association between hospitalization and cognitive decline longitudinally. However, there is very limited data on whether the number and lengths of hospital stay is associated with cognitive outcomes in ageing.

Objective: The aim of this study was to examine the association between cognitive functioning and hospitalization, including the number and length of hospital stays.

Methods: A longitudinal cohort study comparing cognitive function in community-dwelling participants with no admission, one admission and multiple admissions interviewed four times with a total follow-up of 12 years. At baseline, 1,791 participants aged 60-64 years consented to hospital data being linked to their PATH interview data. After excluding participants with a dementia or MCD diagnosis and admissions for rehabilitation at baseline, 1,736 participants were included in the sample. Of these, 556 had at least one admission across the four waves. Measures of immediate recall, working memory, verbal ability, processing speed and a dementia screen were administered. Number of hospital admissions obtained from administrative databases linked to the cohort, and length of stay for each admission were each summed.

Results: Individuals with one or multiple hospital admissions performed significantly lower at baseline and had increased rates of decline compared to those with no hospital admission on immediate recall and the Symbol-Digit-Modalities test. The Mini-Mental State Examination and spot the word were significantly associated with changes over time. Time, comorbid conditions, depression and scores on the digit backwards test were associated with the number of hospital admissions and length of stay.

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Conclusions: There is a strong association between hospitalization and cognitive function longitudinally It is likely that the relationship is bidirectional. Further, well-designed studies are required to evaluate whether hospitalization is causally related to cognitive decline or whether it is part of a cascade of events associated with declining cognition. Given the high rates of hospitalization among older adults and the increasing rates of dementia, these findings are concerning and warrant further investigation to identify possible preventive strategies.

Key words: Hospitalization, cognitive decline, elderly patients

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INTRODUCTION:

In 2013-14, adults aged 65 years and over accounted for 40% of hospital separations across Australia[1]. Similar results were found in the United States with 34.9% of hospitalizations involving adults 65 and older in 2012. Patients over 65 years stay an average of 5.2 days compared to 3.6 days for those aged 18-44 years[2]. Hospitalization is associated with a range of factors which could contribute to cognitive decline including increased rates of depression and anxiety [3, 4], adverse drug events, decreased physical functioning (Dasgupta 2016), sleep deprivation, receiving sedatives and other anticholinergic medications [4], delirium[5, 6], withholding of meals, the acute illness causing the hospitalization[7], persistent and postoperative pain and dehydration. Particular individuals may also be more vulnerable to prolonged or permanent cognitive decline compared to others[8].

Previous research has discovered an association between hospitalization and the development of cognitive decline[4, 9]. For example, studies in Taiwan and America reported that after controlling for illness severity and prehospital cognition, cognitive decline 6 months to one year after discharge from hospital occurred in 40% to over 50% of patients [3, 10]. However we lack evidence on a number of aspects of the cognition-hospitalization association. Currently, it is uncertain how long the change in cognition lasts for post hospitalization. Some research has found that overall cognitive performance in most hospitalized patients with low cognition had improved within one month of discharge[7], whereas other studies have found no improvement in cognitive function during 1 year follow-up [11] to up to 5 years of follow-up[12]. It has also been found that there are different patterns of cognitive change during and after hospitalization[10].

Most of the previous research has focused on post-operative cognitive decline [12, 13] or patients requiring critical care[11, 14, 15]. Of the few studies that have looked at non

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critical illness, one study found that older adults who experienced either critical illness or acute care hospitalization had a greater likelihood of cognitive decline than those who had no hospitalization[9]. This study also found that acute care hospitalization was significantly associated with the development of dementia[9]. Another longitudinal study found that hospitalization for a non-critical acute illness, pneumonia, was associated with a significant increase in moderate-to-severe cognitive impairment[16]. These odds were similar among patients hospitalised for myocardial infarction and stroke. There have been only a small number of epidemiological studies examining cognitive functioning after hospital admission and most of these studies have had short follow-up periods (e.g. less than one year up to six years)[4].

The aim of the present study was to examine the relationship between hospital admission and cognitive performance longitudinally over 12 years. Given the results of previous studies we hypothesized that participants who had one or multiple hospital admissions would have a significant decline in cognition compared to those who did not have an admission. Individuals who had multiple admissions over the 12 years would experience greater decline. Previous research has demonstrated that cognitive impairment is associated with more hospital admissions and longer length of stay[5, 10, 17]. Based on this previous research we hypothesised that the length of hospital stays, or the number of admissions, would increase if participants experienced some cognitive decline.

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METHODS

Participants

This study uses the Personality and Total Health Through Life (PATH) Study data. Participants were community-dwelling individuals from the Australian Capital Territory (ACT) and surrounding regions who were recruited through the electoral roll. Participants were 60-64 years at enrolment (baseline)and followed up every four years. This study examines participants over four assessments, a total of twelve years follow-up time. For more information on the PATH study see [18]. At baseline 2,551 participants completed the interview. Written informed consent was obtained from all participants prior to involvement in the study, and the Australian National University Human Research Ethics Committee approved the study.

PATH data was linked to the ACT Admitted Patient Care (APC) data for the period 1st July 2004 to 30 June 2013. The ACT APC records all inpatient separations from all public and private hospitals in ACT. The ACT APC records were linked to the PATH dataset by the Centre for Health Record Linkage (CHeReL) using probabilistic record linkage methods and ChoiceMaker software [19]. Of the baseline 60 year olds PATH sample who consented to their data being linked (n=1,791) 587 persons had a hospital admission, with a total of 3125 records. The chance of any false positives occurring for this linkage was 3 out of 1,000 records (0.3%).

To ensure that the sample was cognitively healthy prior to hospitalization, 54 participants diagnosed with dementia or any mild cognitive disorder (MCD) at baseline were excluded. As admissions for rehabilitation resulted in a large number of one-day admissions which skewed the data these records were also excluded, resulting in one participant excluded. Of the remaining participants (n=1,736), 556 (32%) had at least one admission

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across the four waves. A flowchart of participant recruitment is provided in the supplementary material.

Clinical Assessment

A cognitive battery was used to screen participants into a sub-study on neurocognitive disorders including Mild Cognitive Impairment (MCI) and dementia [20]. The clinical assessment involved a Structured Clinical Assessment for Dementia, a neuropsychological assessment, and the Clinical Dementia Rating Scale. Diagnoses were formulated from clinical checklists, data from the neuropsychological assessment, and neuropsychological and medical history [21, 22]. The classification of any MCD, which includes MCI, age associated memory impairment, age associated cognitive decline, mild neurocognitive disorder, and other cognitive disorder, has been found to be highly stable over a four-year follow-up and so this general classification was used [23].

Measures

Cognitive function was assessed using the following tasks at each wave. Short-term memory was assessed by immediate recall of the first trial of the Californian Verbal Learning Test.[24] Working memory was assessed using the Digit Span Backwards subtest of the Wechsler Memory Scale [25]. The Spot-the-Word test was used to assess verbal ability [26]. The Symbol-Digit Modalities Test (SDMT) assessed participant's perceptual speed [27]. The Mini-Mental State Examination (MMSE) assessed global cognition [28]. The number of admissions between waves and the length of stay for each admission was summed.

Depression was measured using the Brief Patient Health Questionnaire (BPHQ) [29]. This questionnaire was scored to give a continuous scale from 0 to 27. During the PATH interview participants self-reported any history of arthritis, diabetes mellitus, stroke, high blood pressure, thyroid problems, cancer diagnoses and any heart problems. The number of

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conditions at each wave was then summed to produce the total number of comorbid conditions for each participant.

Statistical analysis

Analyses were performed using SPSS for Windows 22.0 [30]. At wave 4 there were more than 5% missing cases for cognitive tests and depressive symptoms. A significant Little's MCAR test, χ^2 (71) = 529.98, $p<.001$, revealed that data were not missing completely at random so multiple imputation was used to complete the dataset. Cross-sectional analysis at wave 4 comparing participants who had an admission with participants who had not was conducted with generalized linear models. These models used each cognitive test as the outcome measures and adjusted first for demographics and second for depression and number of comorbid conditions.

Linear mixed models were used to estimate the association between hospital admission and cognitive function at the four waves, as well as decline in cognitive function after admission. Statistical analysis was based on previous research [6]. Random effects were included for the intercept, slope before hospitalisation and slope after hospitalisation. A time-varying covariate was used to control for changes in admission status over time. Each model included fixed effects for time before hospitalisation (in years since baseline), time after hospitalisation, age, sex and education and their interactions with time before hospitalisation. To examine the effects of admission on subsequent cognitive function, participants were grouped according to their admission status (none, one admission, and multiple admissions). The group with no hospital admissions was the comparison. A follow-up model tested the effects of depressive symptoms and number of comorbid conditions and their interactions with time before and after hospitalization.

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A generalised estimating equation (GEE) model was then used to test whether a decline in cognitive function was associated with an increase in the number of hospital admissions or length of stay adjusting for baseline cognition. As hospital admission, measured by both length of stay and number of admissions, is a count variable negative binomial with log link function regression models were specified. This GEE model tested length of time and number of hospital admissions as outcome variables. Cognitive tests, demographic variables, depressive symptoms and number of comorbid conditions were all included as predictor variables. Changes in cognitive score over time were tested using interactions with a time varying covariate.

RESULTS

Over the 12 year follow-up period there were 1,180 participants with no admission and 556 with an admission (one or more). Descriptive statistics for participants at their final assessment (wave 4) who had no admission (n= 1,393), one admission (n= 200) or multiple admissions (n= 143) are shown in Table 1. Results from independent t-tests found that individuals with multiple admissions had significantly lower scores on the SDMT (all waves $p<.001$), MMSE (wave 1 and 3 $p<.05$, wave 4 $p<.001$), immediate recall (wave 2 and 3 $p<.05$, wave 4 $p<.001$) digit backwards (all waves $p<.05$), and spot the word (all waves $p<.001$) compared to individuals who had no admission. Individuals who had one admission had significantly lower scores on the SDMT (wave 1, 2 and 3 $p<.05$, wave 4 $p<.001$), MMSE (wave 4 $p<.05$), immediate recall (wave 4 $p<.05$), and spot the word (all waves $p<.05$).

Between waves 1 and 2, 97 participants had a hospital admission with a total number of 181 admissions (range 1-22, mean = 1.87, median = 1) and a total of 692 days spent in hospital (range 1-107, mean= 7.13, median= 2). Between waves 2 and 3, 298 participants had a hospital admission. The total number of admissions between wave 2 and 3 was 555

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admissions (range 1- 9, mean = 1.86, median = 1.00) and the total length of stay was 1,856 days in hospital (range 1- 65, mean = 6.23, median = 2.50). Finally, between wave 3 and 4, 343 participants had an admission, total number of 693 admissions (range 1- 27, mean = 2.02, median = 1.00) and 2,615 total days in hospital (range 1- 124, mean = 7.62, median= 3.00).

The number of participants with one or multiple admissions increased over the 12 years. Between waves 1 and 2, 58 participants had a single admission, 39 had multiple admissions and 1639 participants had no admission. Between wave 2 and 3, 168 participants had one admission and 130 had multiple admissions, leaving 1,438 with no admission. Finally, between wave 3 and 4, 200 participants had a single admission, 143 had multiple admissions and 1,393 had no admission.

Five participants were diagnosed with dementia at wave 3 and 34 participants at wave 4. At wave 2, 55 people were diagnosed with MCD, there were 49 with MCD at wave 3, and 197 had MCD in wave 4. Across all four waves more males were admitted to hospital than females (w1-2: 53 vs 44, w2-3: 163 vs 135, wave 3-4: 187 vs 156).

Association between cognitive decline and hospitalization

The results of the linear mixed model are shown in Table 2. After controlling for all variables participants with multiple admissions were significantly associated with scores on SDMT (p=.016) and immediate recall (p=.026). After adjusting for change over time these individuals were significantly associated with scores on SDMT (p=.015), MMSE (p=.041) immediate recall (p=.002) and spot the word (p=.041). Participants with one admission were significantly associated with changes in immediate recall (p<.001), with changes in SDMT (p=.006) and immediate recall (p<.001). Changes in immediate recall score over time by admission group are shown in Figure 1.

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Association between cognition, length of stay and number of hospital admissions

Results of the two GEE models are shown in Table 3. When all predictor variables were included in the GEE model the following predictors were significantly associated with number of admissions: number of comorbid conditions, depressive symptoms ($p<.001$) immediate recall and digit backwards ($p<.05$). Immediate recall was the only cognitive test to have a significant change over time ($p<.05$).

Number of comorbid conditions, depressive symptoms, digit backwards score and SDMT ($p<.05)$ were significantly associated with length of stay. Digit backwards was the only cognitive score to have a significant change over time ($p<.05$).

DISCUSSION

The aim of this study was to examine the relationship between hospital admission and cognitive performance longitudinally. Our first hypothesis, participants who had one or multiple hospital admissions would have significant declines in cognition compared to those not admitted, was supported. T-tests found that individuals with one or multiple admissions had significantly lower scores on all cognitive variables. Our longitudinal analysis found that multiple admissions were significantly associated with cognition at baseline for two cognitive tests (immediate recall and SDMT) and significant declines over time for four tests (immediate recall, SDMT, MMSE and STW). Participants with one admission had poorer cognition at baseline for immediate recall only, but declines in both immediate recall and SDMT.

We also hypothesized that the length of hospital stay or number of admissions would increase if participants experienced some cognitive decline. Decreases in immediate recall

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and increases in digit backwards were significantly associated with the number of hospital admissions. Increases in the SDMT and digit backwards were associated with length of stay.

Our study found that individuals with one or multiple admissions had a decline in cognition compared to those who did not have admission. Only a few other studies have looked at changes in cognitive decline after non-critical hospitalization in individuals without dementia longitudinally [6, 9, 16, 31]. One of these studies found that the rate of cognitive decline accelerated after hospitalization by more than 2.4-fold and that more severe illness, longer hospital stay and older age contributed to a faster rate of decline after hospitalization [6].

This study has some limitations. Firstly, there is a four-year interval between cognitive assessments. As previous studies have found that cognition can improve one to two months after admission this extensive time gap between assessments limits our ability to track short-term changes in cognition around the time of hospital admission [7]. This may have resulted in underestimation of the association between hospital admission and cognitive decline. Secondly, data on hospital admissions was only available to the authors from 1 July 2004 but baseline interviews were conducted in 2001-2002, therefore 18 months of possible admissions is missing. Due to missing data we cannot test if more admissions or longer hospital stay at baseline resulted in changes in cognition. As we do not have data on hospitalization pre-baseline we cannot ascertain whether declines in cognition preceded the admission.

Previous studies have found an association between cognition and surgery [3, 13], the type of admission [8, 9, 32], and delirium during hospitalization or after surgery [33, 34]. For example, previous research has found that delirium is associated with an 8-fold increase in

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incident dementia within the next three years and accelerated decline in MMSE scores [35]. Our study lacked data on delirium and surgery so we were unable to evaluate these factors.

Although our study controlled for a number of comorbid conditions, it did not examine whether cognitive decline was more prominent for particular diagnoses or patient groups. For example, studies have found that hospitalization for pneumonia, myocardial infection or stroke is associated with subsequent cognitive impairment [16] and higher rate of dementia [31, 36]. Examining groups based on diagnoses would have resulted in low power due to small sample size. Medical conditions that 'lead to hospital admissions may also indicate overall frailty in individuals. Studies have demonstrated that frailty in older adults is associated with risk of dementia as well as general cognitive impairment [37, 38]. As the condition, and its associated treatment effects, that led to the hospitalization may be associated with increased cognitive decline it is important for future research to examine the impact of different conditions [39].

Medications used during hospitalization such as anticholinergics, narcotics and benzodiazepines are commonly recognised as causing cognitive impairment [40, 41]. This study could not control for medication use in participants due to data not being available. Participants data was only linked with data from ACT hospitals, therefore we cannot control for admissions that may have occurred elsewhere.

Despite its limitations this study has many strengths. This is the first study, to the authors' knowledge, which has examined the difference in cognitive decline between participants with no admission, one admission and multiple admissions. Previous studies have conducted follow-up tests of individuals hospitalised [12, 16, 42] or compared participants who were hospitalised versus those not hospitalised [6, 9, 39].

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Previous research has relied on either the MMSE only [3, 10, 34, 42, 43] or similar screening instrument [9, 16] or a composite of cognitive tests to assess cognition [6]. Using only one instrument to measure cognition may not test the full spectrum of cognition and composite scores may have methodological problems such as lack of reliability. In cognitively healthy adults hospitalisation may affect some cognitive functions but not others [6, 9]. In this study, the authors have used a range of separate cognitive tests to measure cognitive decline resulting in a better representation of cognitive function. This study used a relatively large sample to examine the association between cognitive decline and hospitalization over a long period of time. Only a few other studies have examined cognitive decline after hospitalization over such a long follow-up period [6, 9, 16]. Previous research has found that participants with the worst decline in cognition already had a mild degree of AD [42]. This study controlled for previous cognitive impairment by excluding participants with Alzheimer's or MCD at baseline. The sample was also relatively young at baseline so we have a measure of their cognitive function prior to most age-related decline.

CONCLUSION

This study found that individuals with one or multiple hospital admissions had poorer baseline cognitive function and increased rates of decline compared to those with no hospital admission. Given the high rates of cognitive impairment in the population and the need to identify risk factors and risk reduction strategies[44], these findings warrant serious attention. A high proportion of older adults are exposed to hospitalization and any preventive strategies will therefore have widespread impacts. Research is needed to identify aspects of hospitalization that increase or accelerate cognitive decline as there may be clear preventive strategies that can be implemented, for example, reducing dosage of anticholinergic medication during hospitalization or programs for de-prescribing at discharge. Further research is needed that samples smaller time-intervals to identify when improvements or

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declines occur and other pre-and post-hospital factors contributing to poor cognitive outcomes.

ACKNOWLEDGEMENTS:

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Table 1. Descriptive statistics at wave 4 by participants with none, one or multiple admissions

	No admission	One admission	Multiple admissions
N	1393	200	143
Male %	42.3	43.4	44.6
Age in years (*M, SD*)	75.03 (1.49)	75.04 (1.60)	75.18 (1.62)
Education in years (*M, SD*)	14.18 (2.66)	13.87 (2.51)	13.72 (2.78)
No. comorbid (*M, SD*)	1.92 (1.18)	2.22 (1.26)	2.51 (1.35)
SDMT score (*M, SD*)	46.84 (9.71)	43.32 (10.02)[a]	44.20 (9.86)[a]
MMSE score (*M, SD*)	29.13 (1.44)	28.72 (1.88)[a]	28.64 (2.15)[a]
Immediate recall score (*M, SD*)	5.45 (2.55)	4.76 (2.66)[a]	4.74 (2.80)[a]
Digit backwards score (*M, SD*)	5.28 (3.21)	4.77 (3.43)[a]	4.72 (3.26)[a]
Spot the Word score (*M, SD*)	53.73 (5.21)	52.45 (5.15)[a]	52.36 (5.80)[a]
Depressive symptoms (*M, SD*)	2.62 (2.79)	3.21 (3.29)	3.87 (3.46)
No. Admissions (*M, SD*)	NA	1.00 (0.00)	3.45 (3.08)
Length of stay in days (*M, SD*)	NA	3.85 (5.85)	12.90 (15.93)

Note: M= Mean; SD= Standard Deviation; SDMT= Symbol Digit Modalities Test; MMSE= Mini Mental State Examination. Number of Admissions and Length of stay is across all four waves, a= significantly different to individuals with no admission (*p*<.05)

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Table 2. Results from Linear Mixed Models, Hospital admission status on rate of cognitive decline over 12 years

	Immediate recall	SDMT	MMSE	STW	Digit backwards
At baseline (intercept)					
Multiple admissions	0.82 (0.14, 1.50)*	2.47 (0.46, 4.47)*	0.32 (-0.11, 0.75)	0.45 (-0.03, 0.12)	-0.07 (-0.78, 0.63)
One admission	1.30 (0.68, 1.91)**	1.58 (-0.19, 3.35)	0.14 (-0.23, 0.52)	-0.30 (-0.97, 0.36)	-0.22 (-0.86, 0.42)
By time (slope)					
Multiple admissions	0.18 (0.06, 0.29)*	0.41 (0.06, 0.76)*	0.08 (0.00, 0.16)*	0.13 (0.01, 0.26)*	-0.03 (-0.15, 0.09)
One admission	0.19 (0.10, 0.29)**	0.40 (0.12, 0.68)*	0.04 (-0.02, 0.10)	-0.01 (-0.12, 0.09)	-0.04 (-0.14, 0.06)

Note: Effects are beta weights with 95% CI from linear mixed models (reference group is no admission). Model adjusted for time, age, sex, education, depression and number of comorbid conditions. N=1736. SDMT= Symbol Digit Modalities test; MMSE= Mini Mental State Examination; STW= Spot-The-Word Test. **p<.001, *p<.05

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Table 4. Results of GEE models, number of admissions and length of stay as outcome variables

	Number Admissions			Length of Stay		
	B	Exp(B)	CI	B	Exp(B)	CI
Gender=Male	0.20	1.22	0.94, 1.57	0.06	0.98	0.77, 1.47
Age	0.10	1.01	0.94, 1.09	0.06	1.06	0.96, 1.17
Time	0.47	1.60	0.96, 2.67	0.36	1.43	0.86, 2.39
Education	0.01	1.01	0.97, 1.06	0.03	1.03	0.97, 1.10
SDMT	-0.02	0.98	0.96, 1.01	**0.00***	0.96	0.93, 0.99
MMSE	0.07	1.07	0.89, 1.30	0.04	1.04	0.84, 1.30
Immediate Recall	-0.17*	0.85	0.75, 0.96	-0.14	0.87	0.66, 1.15
Digit Backwards	0.13*	1.14	1.01, 1.29	0.14*	1.15	1.01, 1.31
STW	-0.02	0.98	0.94, 1.03	-0.02	0.98	0.93, 1.04
No. Comorbid	0.22**	1.25	1.13, 1.37	0.20*	1.22	1.07, 1.38
Depression	0.06**	1.06	1.03, 1.10	0.11*	1.11	1.04, 1.19

Note: CI= confidence interval; SDMT= Symbol Digit Modalities Test; MMSE= Mini Mental State Examination; STW= Spot-The-Word. **p<.001, *p<.05

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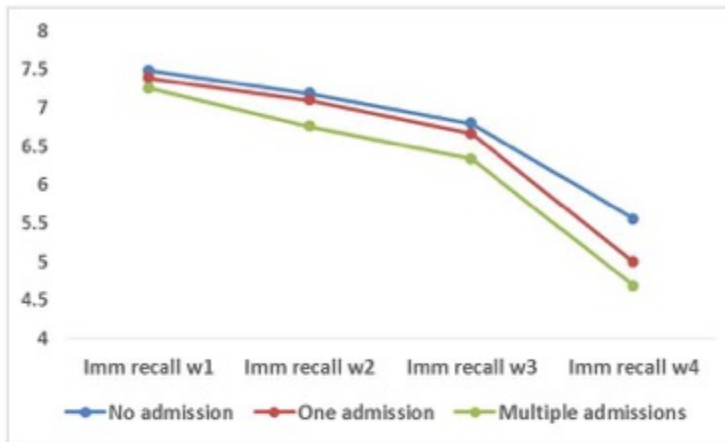
Figure 1. Declines in Immediate Recall score over 12 years follow-up by admission group (none, one or multiple)

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6.3 Summary

The manuscript presented within this chapter, paper 4, discusses the association between cognitive impairment and the use of hospital services. It demonstrates that individuals with one or multiple hospital admissions performed significantly lower on cognitive tests at baseline and had increased rates of cognitive impairment compared to those with no hospital admissions. Decline in some cognitive tests was also significantly associated with longer lengths of stay and increased hospital admissions.

According to the Andersen-Newman model, need factors and how sick an individual is or perceives themselves, are the largest drivers of healthcare service use. In paper 4 use of hospital services had a bi-directional relationship with cognitive impairment. Individuals with one or multiple admissions had the greatest decline in several cognitive tests over time, even after adjusting for other comorbid conditions. This suggests that there is a complex relationship between need and hospital use. Paper 4 controlled for basic predisposing factors, such as age, sex and education, which may impact on hospital use. It did not, however, examine other predisposing or enabling factors that may have contributed to participants going to a public hospital, such as their financial status or health insurance status. The association between health service use and these factors will be examined in the next chapter.

Another limitation of this paper is that the authors lacked diagnostic data from the hospital admissions so we cannot determine the type and severity of illness during their hospital stay. It may be that hospitalisation is a proxy for the effects of serious medical illness and their treatment upon cognition. Due to the lack of diagnostic data we were also unaware of, and could not control for, delirium or other cognitive problems during hospital admission. Future research could examine the association between illness type and severity with cognitive impairment.

As stated in Mathews et al. (2013) it has been difficult for studies to establish a relationship between cognitive impairment and hospitalisation and determine the nature and direction of this

relationship. Future research needs to investigate the nature and direction of this relationship through different study designs. For example, studies could examine the association between hospital use and individuals at varying levels of cognitive impairment; cognitive status after hospitalisation in different age groups; or examine difference in cognition of individuals in different disease states or diagnoses groups.

There has been very little evidence on the relative contributions of the many risk factors associated with cognitive impairment (Mathews et al., 2013). Future research could examine the impact on cognition of medications received during hospitalisation, such as anaesthesia, anticholinergics, narcotics or benzodiazepines and the presence of delirium. Individual factors, such as comorbid conditions, overall frailty of the individual and stress could also be examined. These risk factors are associated with hospitalisation but could also be contributing to decline in cognition.

The paper in this chapter has used linked data from one hospital, Canberra Hospital, to examine declines in cognition over a long period of time. Due to this design we do not have information on admission status to other hospitals, such as private or interstate hospitals. Future research could expand on this design by using data from hospitals nationally. This research could also link other external datasets, such as the Pharmaceutical Benefits Scheme, to gain a better understanding of participants.

The findings from this paper could provide information to policy makers to improve current policies and programs. For example, these findings provide support for screening, detection and management of cognitive impairment and, given its impact on cognition, delirium in hospitals. These findings also demonstrate the need for strengthening care programs for people with cognitive impairment in hospitals. The issue of screening, detection and care of people with cognitive impairment is discussed in detail in Chapter 8.

This chapter has discussed the association between hospital use and cognitive impairment. The next chapter expands on these research findings by discussing the factors associated with the use of

GP, hospital and ED services and how these differ for individuals with dementia, MCD or who are

cognitively healthy.

Chapter 7: PREDICTORS OF HEALTH SERVICE USE AND COGNITIVE DECLINE

7.1 Introduction

The previous two chapters discussed the association between cognitive impairment and GP use and admitted patient hospital use. The papers included in each of these previous chapters found that declines in cognitive function may be associated with increased use of these health services and that being hospitalised may impact on cognition. This chapter examines whether certain factors in an individual's life predict their use of healthcare services, and how this differs when an individual has cognitive impairment.

7.2 Paper 5: Predictors of healthcare service use in participants with Mild Cognitive Disorder

Previous research has found that certain factors can influence use of health care services. For example, studies from the US have found increased ED visits to be linked with loneliness, vulnerability and lack of access to family support in older people (Lowthian et al., 2011). The quality of social interactions has been found to affect health and health-related behaviour. Negative feelings or dysfunction between members in social networks can increase stress and affect a person's overall sense of well-being, increasing use of GP services and readmission to hospital. On the other hand, positive social support may have a 'buffering' affect that mitigates the effect of life stresses, contributing to good health. Furthermore, social networks may directly affect health through provision of information about health services, encouraging health service use and supporting healthy behaviours (Mistry et al., 2001).

Other factors that may affect use of services include finances and proximity to services. Research has found that low household income is a barrier to using healthcare services (Blackwell, Martinez, Gentleman, Sanmartin, & Berthelot, 2009; Gong, Kendig, & He, 2016; National Health Performance Authority, 2015). A study from South Korea using a nationwide longitudinal study found that the

level of health insurance held affected length of time spent in hospitals, with less coverage resulting in lower healthcare utilisation (Kim & Lee, 2016). Living in an urban area significantly increases the likelihood of people contacting a GP (Babitsch, Gohl, & von Lengerke, 2012).

The paper below uses the Andersen-Newman model to examine factors that can influence health service use in people with different levels of cognitive functioning (normal, MCD and dementia). This model posits that there are individual characteristics, divided into three factors, that contribute to the type and volume of health service a person uses (Andersen & Newman, 1973). The three factors are: 1) predisposing, 2) enabling, and 3) need. These factors are described in more detail in Chapter 2.

The Andersen-Newman model has been extensively used in studies which examine use of health services (Babitsch et al., 2012). A number of these studies have examined use in the elderly population (Korten et al., 1998; Parslow et al., 2004) and use by people with dementia (Forbes, Morgan, & Janzen, 2006; Toseland et al., 2002). However, very few studies examine use across the continuum of cognitive, from normal cognition dementia. The aim of this paper is to examine predictors of usage in individuals with MCI or dementia compared to those who are cognitively healthy.

Statement of authorship

Predictors of healthcare service use: a cross-sectional study examining use in participants across the cognitive continuum. *Prepared for submission.*

Lily O'Donoughue Jenkins (PhD candidate)

Developed study concept and design; initiated data linkage process with CHeReL; submitted ethics approval and project proposal for linkage of ACT Admitted Patient Care data and PATH data to CHeReL; prepared spreadsheet with hospital data provided by CHeReL, health and sociodemographic variables extracted from PATH; analysed and interpreted data; drafted and edited the manuscript; acted as corresponding author. I certify that the statement of contribution is accurate

Signed…………………………… Date…………………….

Kaarin J. Anstey (Principal supervisor)

Assisted in developing the study concept and design; drafted and provided critical revision of the article; assisted in interpretation of data analysis; provided final approval of the manuscript to be published. I certify that this statement of contribution is accurate and permission is given for Lily O'Donoughue Jenkins to include this paper in this thesis for examination towards the Doctor of Philosophy

Signed…………………………… Date…………………….

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ABSTRACT

Introduction: This study uses the Andersen-Newman model to examine factors that can influence health service use in people with different levels of cognitive functioning (normal, MCI and dementia)

Methods: 1,616 participants who completed the PATH study in Canberra and provided consent for their data to be linked with Medicare, Emergency and/or Hospital data were investigated. Follow-up data was collected after 4 years. A cognitive screening battery was used to screen participants into a substudy of MCD and dementia.

Results: Presence of MCD significantly increased same day admissions (β= 0.75, SE= 0.35, p<.001), dementia significantly increased overnight admissions (β= 0.494, SE= 0.25, p<.05). Having dementia significantly increased length of stay in hospital (β= 0.661, SE= 0.18, p<.001), whereas, MCD (β= -0.457, SE= 0.14, p<.05) significantly decreased length of stay. For all participants need factors predominately impacted on service use compared to predisposing or enabling variables.

Conclusion: This paper has found that factors which may impact on health care service use differ between individuals with MCD or dementia to those who are cognitively healthy. Gaining an understanding of the reasons why older adults with cognitive impairment use health care services and opportunities for interventions is essential to planning informed strategies to meet the health care needs of an ageing population

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INTRODUCTION

The number of Australians aged 65 years and over has increased rapidly and it is projected that by 2064 this age group will double to constitute approximately 28 per cent of the Australian population [1]. As the ageing population continues to increase, so too will the prevalence of dementia and mild cognitive impairment (MCI) [1 2].

Previous research has found that lower cognitive function is significantly associated with general practitioner use, especially if individuals have a comorbid condition such as depression or anxiety [3]. Studies have also found an association between cognitive impairment and hospital use, with cognitive impairment predicting both increased number of hospital admissions and longer hospital stays [4-7]. Cognitive impairment has also been found to be a predictor of emergency department visits [4 8]. Given these findings, it is expected that as the prevalence of dementia and other cognitive impairments increases so too will the demand for these health care services [9 10].

To ensure that health services provided to individuals with cognitive impairment are sufficient we need to examine the influence of factors which may predict the use of health services in this population. According to the health behaviour model developed by Andersen and Newman [11] an individual's decision to obtain healthcare is influenced by three groups of factors: predisposing, enabling and need. Some individuals are more likely to use health services than others because of individual characteristics which existed prior to the onset of illness [11]. These predisposing factors may include demographics, such as age, marital status or sex, or social structure, such as level of education and ethnicity. Another characteristic of predisposing conditions is beliefs or attitudes towards disease, about medical care or seeking help [12]. An individual's thoughts about health and health systems may ultimately influence their behaviour [11]. Enabling factors are conditions that obstruct or enable service use [13]. Enabling factors include income, having health insurance and having access to health services [12]. Finally, the individual must have or perceive an illness or its

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probability of occurrence to use health services [11]. Need can be measured by either individual's perceived level of illness or be professionally evaluated [12].

A large amount of research has examined to what extent predisposing, enabling and need variables explain service use. This research provides contradictory results on the impact of these variables. Most studies have found that need variables, such as number of comorbid chronic diseases and patient-perceived physical health, are the most important predictors of health care service use [14-16]. For example, some studies with older people have found that those with more health and psychosocial problems reported higher health and social service use [12 17-19]. Predisposing factors have been found to be a significant, but not a strong contributor of service use [14 20]. One of these predisposing factors, social support, has been found to have a small effect on contact with a GP in some studies [12] but have no predictive value as a determinant of service use in others [14]. However, it has also been found that social support reduced the use of some formal health services [12] especially in particular cultures [21]. When enabling factors were measure by income, health insurance or place of residence they have been found to have either no effect on service use [16] or were significantly associated with health service use [22]. In one study enabling factors explained more variance in service use than either need or predisposing factors [23].

Although a number of studies have looked at the predictors of healthcare service use in the elderly population [14 15 20], very few have compared the predictors of health service use between people with dementia or with any mild cognitive disorder (MCD) to those who are cognitively healthy. Studies which have examined the impact of cognition on healthcare service use have only examined people with dementia [23 24], used nursing homes residents for their sample [4 25] or had methodological flaws. For example, a number of studies have only used the Mini Mental State Examination, or an adaptation of it, rather than a neuropsychological assessment [14 21 26 27]. Although the MMSE is used for screening for cognitive impairment it is not sensitive to subtle cognitive decline [27]. Moreover,

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individuals with MCD are at a higher risk of remaining so or progressing to dementia so it is important to examine this population.

The aim of this study is to compare the factors that contribute to the use of healthcare services in individuals with dementia, any MCD and those who are cognitively healthy. The factors within this paper were divided according to the Andersen-Newman model, with predisposing, enabling and need factors being predictors of service use. The first hypothesis was that the predisposing factors social support and marital status would impact on service use of MCD or dementia participants more than non-MCD participants. For this hypothesis, it was expected that being married and having positive social support would increase usage.

Secondly, it was hypothesised that enabling factors, including having financial problems or having no health insurance, would result in non-MCD participants using less services but have no effect on MCD or dementia participants use. Thirdly, it was predicted that need factors would have the greatest impact on health service use for all participants regardless of cognitive status.

METHODS

Participants

The Personality and Total Health Through Life (PATH) Study, and the clinical Health and Memory sub-study, surveys participants from three cohorts, 20-24 years, 40-44 years and 60-64 years. Participants reside in Canberra and surrounding regions and were recruited through the electoral roll. Each cohort was interviewed, in turn, over a one-year period and followed up every four years. For more information on the PATH study see [28 29]. This investigation focusses on the older cohort between waves 3 and wave 4 (interviews completed in 2010 and 2014). At baseline 2,551 participants completed the interview. After excluding participants who were not interviewed at wave 4 (n= 907) or did not provide

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consent for their data to be linked with Medicare, ED and/or Hospital data (n= 28) there were

1,616 participants remaining. The analysis reported below is based on these 1,616

participants who completed the interview at wave 3 and for whom data on health services use

were available at wave 4. Written informed consent was obtained from all participants prior

to involvement in the study, and the Australian National University Human Research Ethics

Committee approved the study.

Clinical Assessment

A cognitive battery was used to screen participants into a sub-study on neurocognitive

disorders including Mild Cognitive Impairment (MCI) and dementia [30]. Participants were

selected for clinical assessment if they had any of the following: (i) a Mini-Mental State

Examination (MMSE) [31] score ≤ 24 at wave 4; or (ii) performance on one or more

cognitive tests ≤ 6.7th percentile at wave 4 (Immediate recall and/or Delayed recall of the

California Verbal Learning Test [32], Symbol Digit Modalities Test [33], Purdue Pegboard

dominant, Purdue Pegboard non-dominant, Purdue Pegboard both hands [34], Choice

reaction time, simple reaction time [35], F words, A words, Boston naming Test, Digits back,

Trails B, Stroop Words, Stroop colour-word); and iii) subjective decline (scores ≤ 25 on the

Memory and Cognition Questionnaire), or evidence of decline (>3 point decline in MMSE

score since Wave 3), or evidence of consistent cognitive impairment across time (MMSE ≤

24 at Waves 3 and 4).

The clinical assessment involved a Structured Clinical Assessment for Dementia, a

neuropsychological assessment, a detailed informant interview and the Clinical Dementia

Rating Scale. Diagnoses were formulated from clinical checklists, data from the

neuropsychological assessment, and neuropsychological and medical history [36 37]. The

classification of any MCD, which includes MCI, age associated memory impairment, age

associated cognitive decline, mild neurocognitive disorder, and other cognitive disorder, has

been found to be highly stable over a four-year follow-up [38] and so this general

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classification was used. A description of the neuropsychological assessment and diagnostic

criteria is included in the online supplementary material. Cognitive status at wave 4 was used

to group participants. Of the 1,616 participants, 169 were diagnosed with MCD and 67 were

diagnosed with dementia according to the DSM-V.

Measures

Healthcare services (outcome variables)

Outcome variables included GP visits, hospital admissions and ED presentations

measured between waves 3 and 4. Data on GP visits data sourced by linking consenting

participants' data to their records from the Medicare Benefits Schedule (MBS). The MBS is a

list of Medicare services subsidised by the Australian government and includes the date of

consultation and the type of service provided. The analysis considers the total number of GP

visits for the period 6 months prior to and 6 months after the PATH interview, this approach

has been used in previous research [39]. The measure was based on specific Medicare item

codes, which account for the majority of GP visits.

To obtain information on hospital admission, PATH data was linked to the ACT

Admitted Patient Care (ACT APC) data for the period 1st July 2004 to 30 June 2013. The

ACT APC records all inpatient separations (discharges, transfers and deaths) from all public

and private hospitals in ACT. From our sample 164 participants had a same day admission

and 214 participants had an overnight admission at wave 4. The total number of same day

admissions, number of overnight admissions, and overall length of hospital stay recorded

between wave 3 and wave 4 were used as outcome variables.

Information on ED presentations was obtained by linking PATH data to the ACT

Emergency Department Information System (ACT EDIS) for the period 1st July 2005 to 30th

June 2013. The ACT EDIS provides information about patient presentations to the

emergency departments of public hospitals in the ACT, including source of referral to ED.

Only 149 participants had an ED presentation between waves 3 and 4. The analysis uses the

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total number of ED visits recorded.

Predictor factors

Predisposing variables

Participants self-reported sex, age, total years of education, whether they lived alone and marital status. Positive and negative interactions with spouse, family and friends was measured using the social support scale [40]. The social support scale includes six separate indices of support and negative social interactions which are scaled so that the lowest scores are coded 0 and the highest scores are coded as 1. Positive and negative interactions for spouse, family and friends were included in the analyses separately. Level of household responsibility was measured by participant's assessment of the extent to which, in their household, they were responsible for household chores and financial management. For this measure participants rated their responsibility as "Fully responsible 100%," "mostly responsible 75%," "partly responsible 25%," or "not at all responsible 0%." The responses were summed to give a total role strain score.

Mastery was measured using the Pearlin's Mastery Scale [41]. This scale consists of 7 statements, positively and negatively worded, which participants respond to on a four-point scale from 1= "Strongly Agree" to   4= "Strongly Disagree". Negatively worded statements were reverse coded and the scores summed. A low score suggests a high level of control and a high score suggests a low level of control.

Enabling variables

Participants self-reported if they had financial difficulties, if they had health insurance and if their only income was the pension.

Need variables

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Participants self-reported if they suffered from any cancer, thyroid, arthritis, epilepsy, asthma (including chronic bronchitis and emphysema), diabetes, high blood pressure, heart trouble, kidney disease, TIA or had had a stroke. These conditions were then summed to give a total number of comorbid conditions. Self-assessed physical health was obtained from participant's responses to the 12-item short-form health survey (SF-12) with higher scores indicating better physical health [42]. Functional status was assessed using the Instrumental Activities of Daily Living (IADL) scale. Participants indicated if they required help on the following four activities: preparing meals, shopping, using the telephone and taking medications. Scores were coded as 0= no help needed or 1= help needed and summed. IADL total scores ranged from 0 to 4 with higher scores indicating greater functional disability. The Goldberg depression and anxiety scale was used to assess participant's level of depression and anxiety symptoms [43]. Substance use measures included whether participants currently smoked cigarettes, whether they consumed alcohol at hazardous or harmful levels (more than 28 standard drinks per week for men and more than 14 standard drinks per week for women) and whether they abstained from alcohol. Participants self-reported how many hours of vigorous, moderate and mild exercise they did each week. Based on this participants were classified into 'vigorous activity,' 'moderate activity,' and 'mild or none activity.'

Statistical Analysis

Statistical analysis was performed using SPSS for windows 22.0. Two sets of regression analyses were used to explore the contribution of blocks of need, enabling and predisposing factors in affecting health service use by dementia, MCD and non-MCD participants. The first set used logistic regression analysis with backward stepwise likelihood ratio method to identify factors associated with number of GP visits, number of same day admissions, number of overnight admissions and emergency department presentations. These were categorised into 'no admission/visit/presentation' and 'one or more admission/visit/presentation.'

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The second set of analyses used a multivariate negative binomial model to examine the contribution of predisposing, enabling and need variables on use of each service. Each health care variable had four regressions, firstly with age only, then adding the predisposing factors, then enabling factors and finally adding the need factors. The reference group was the absence of the condition under interest (e.g. smoker vs non-smoker, vigorous and moderate activity vs mild or none activity). Manual backward stepwise deletion was then performed with non-significant variables removed. The predictor variables MCD and dementia were kept in whether they were significant or not.

RESULTS

Descriptive statistics and outcome variables at baseline for participants with MCD, dementia and non-MCD are shown in Table 1. Participants with MCD or dementia were more likely to be male and have lower levels of education than those who were cognitively healthy.

Logistic Regression analysis Dementia, MCD and non-MCD participants

The final variables in the logistic regression model for ED, same day admissions and overnight admission, by cognitively healthy, MCD and non-MCD participants, is shown in Table 2. Due to small sample size and problems with correlation the logistic regression for GP use by individuals with MCD and dementia did not result in any significant variables. Therefore, logistic regression models for GP use are not reported. Blocks of the predisposing and need variables significantly contributed to the model, except not for ED or same day admission use in dementia participants.

Generalised Estimating Equation (GEE) models

GEE models were built for healthcare service (GP use, number of same day admissions, number of overnight admissions, length of hospital stay and emergency department presentations). For each service the model adjusted for predisposing variables

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first, enabling variables were then added, and finally need variables were added.

General Practitioner use

Neither MCD nor dementia was associated with GP use. Age (β= 0.048, SE= 0.02, p<.05), being a smoker (β= 0.433, SE= 0.12, p<.001), having anxiety (β= 0.066, SE= 0.01, p<.001), and number of comorbid conditions (β= 0.181, SE= 0.02, p<.001) increased GP visits. Higher education (β= -0.031, SE= 0.01, p<.05), being on a pension only income (β= -0.197, SE= 0.09, p<.05) and not having health insurance (β= -0.054, SE= 0.07, p<.001) decreased usage.

Same day admissions

Dementia was not associated with same day admissions, however, MCD increased same day admissions (β= 0.75, SE= 0.35, p<.001). Being male (β= -0.44, SE= 0.18, p<.05), having no household responsibility (β= -0.56, SE= 0.25, p<.05) and positive family support (β= -0.213, 0.06, p<.001) decreased same day admissions. Having financial problems (B= .685, SE= 0.21, P<.05), higher levels of disability (β= 1.311, SE= 0.15, p<.001) and worse self-rated physical health on the SF-12 (β= -0.047, SE= 0.01, p<.001) increased same day admissions

Overnight admissions

Dementia was significantly associated with increases in overnight admissions (β= 0.494, SE= 0.25, p<.05), MCD was not associated. Being male (β= -0.338, SE= 0.13, p<.05), having positive family support (β= -0.129, SE= 0.05, p<.05) and having no health insurance (β= -0.358, SE= 0.13, p<.05) decreased usage. Having no responsibility of household finances (β= 0.456, SE= 0.20, p<.05) and worse self-rated physical health on the SF-12 (β= -0.044, SE= 0.01, p<.05), increased usage.

Emergency Department presentations

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Neither MCD nor dementia was significantly associated with ED use. The number of comorbid conditions (β= 0.150, SE= 0.04, p<.001) and worse self-rated physical health on the SF-12 (β= -0.034, SE= 0.01, p<.001) increased ED use. Higher education was the only variable that decreased usage (β= 0.150, SE= 0.02, p<.001).

Length of hospital stay

Dementia significantly increased length of stay in hospital (β= 0.661, SE= 0.18, p<.001), whereas, MCD (β= -0.457, SE= 0.14, p<.05) significantly decreased length of stay. The significant variables for length of stay are shown in Table 3.

DISCUSSION

This study aimed to examine which predisposing, enabling and need factors contributed to the use of healthcare services in individuals with dementia or MCD compared to those who are cognitively healthy. It was found that individuals with dementia had the highest mean number of overnight admissions, length of stay, GP visits and ED presentations. MCD participants had the highest mean number of same day admissions.

Examining how each factor contributed to use for all participants, it was found that the number of need factors contributing to service use was not proportionately higher than predisposing or enabling factors. In the final logistic regression models health insurance, an enabling variable, significantly increased overnight admissions in dementia participants and decreased same day admissions in MCD participants, however this was not significant.

Having positive social support may directly affect health through the provision of information about health services, encouragement of health service use and support of healthy behaviours [44 45]. This study found that positive social support increased use ED, of same day and overnight hospital admissions for MCD and dementia participants. However, this study found that positive family support also decreased same day admissions for dementia

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participants. Individuals who have good social support may have decreased use of health services because they know they can rely on family or friends to care for them at home. For example, a study based in Taiwan found that declines in cognition were associated with increased use of informal support (i.e. help from their family or friends) but that formal service use was not associated [21].

Having negative social support from friends decreased usage of ED and same day admissions for MCD participants, and ED for dementia participants. As there has been very little research examining the association between social support and healthcare use in cognitively impaired individuals we cannot determine if this is a usual finding. Given the contradictory results in relation to social support and use of health services future research should examine this association further, including the direction of the relationship and if it is impacted by other factors.

Previous studies differ in their classification of predisposing and enabling variables. Some studies define social support as an enabling factor [13 14 24] whereas in this study and others it is classified as a predisposing factor [12 20]. Differences in classification may be due to variables playing a dual role in influencing health service use [46].

Research on health service utilisation in older populations suggests that need factors, including poorer physical and mental health, are the most powerful predictors of service use than predisposing or enabling characteristics [14 20 47 48]. This study found that need variables were no more predominant in the final models than enabling or predisposing factors. For example, in a previous study, 65% of older patients stated that declines in IADL functioning directly contributed to their ED visit [49]. In this study declines in IADL did increase same day hospital admissions but not overnight admissions, GP or ED visits.

Supply-side factors could also contribute to an increase demand on health care services. For example, lack of access to primary care services or inconvenient primary care out-of-hours services could decrease visits to a GP [50]. Individuals may also prefer to see one

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health care over another. For example, evidence suggests that having access to a primary care provider decreases presentations to an ED [49]. This study did not examine whether physical proximity or access to particular services impacted on use of health care services. This study also did not control for use of other health services, for example medical phone lines, internet resources, geriatrician or psychiatrist or walk in clinics.

This study has examined participants from one region in Australia. The ACT has the highest average income, highest level of employment, highest education and highest health status of all the states and territories. At the time of this study the ACT also had the second youngest population. These sociodemographic factors mean that these results may not be generalizable to other regions in Australia. Future research could expand this study to involve participants nationally. Another limitation of this study is that it did not examine illness severity, future research should examine the impact of illness severity on use of service and cognitive status.

CONCLUSION

This study has examined predictors of health care service use in individuals with MCD or dementia compared to individuals who are cognitively healthy using the Andersen-Newman model. As the ageing population continues to increase, so too will the prevalence of cognitive impairment. By examining what predicts use of health services in individuals experiencing cognitive impairment we can develop strategies to target these individuals, ensure that the care provided is sufficient and provide other support options.

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Healthcare service use across the cognitive continuum

Table 1. Descriptive statistics and service use data for individuals with MCD, dementia and cognitively healthy (non-MCD)

	Non-MCD	MCD	Dementia
Male n (%)	702 (50.9%)	91 (53.8%)	40 (59.7%)
Married n (%)	997 (72.2%)	121 (71.6%)	48 (71.6%)
Age (SD)	70.56 (1.48)	70.66 (1.52)	70.55 (1.56)
Education (SD)	14.43 (2.46)	13.9 (2.90)	13.93 (2.67)
No. comorbid conditions (SD)	2.00 (1.28)	2.21 (1.50)	2.18 (1.53)
No. same day admission (SD, range)	0.15 (0.83, 0-24)	3.4 (39.78, 0-497)	0.21 (0.55, 0-3)
No. Overnight admissions (SD, range)	0.22 (0.76, 0-11)	0.23 (0.68, 0-5)	2.33 (6.15, 0-38)
Length of hospital stay days (SD, range)	1.47 (9.41, 0-201)	1.16 (3.99, 0-29)	2.33 (6.15, 0-38)
No. GP visits (SD, range)	9.01 (14.35, 0-179)	9.60 (11.56, 0-99)	13.24 (26.40, 1-196)
No. ED presentations (SD, range)	0.43 (1.30, 0-28)	0.59 (1.51, 0-12)	0.62 (1.55, 0-11)

Note: MCD= mild cognitive disorder, SD= standard deviation, ED= emergency department

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Healthcare service use across the cognitive continuum

Table 2. Final variables in logistic regression models for emergency department, same day and overnight admissions by non-MCD, MCD and dementia participants

	Emergency Department	Overnight admissions	Same day admissions
Non-MCD	Mastery* (β = -0.44, SE= 0.02)	Education (β =-0.03, SE= 0.03)	Education (β = -0.06, SE= 0.04)
	Anxiety* (β =0.09, SE= 0.04)	Mastery (β =-0.02, SE = 0.03)	Positive partner (β= -0.08, SE= 0.05)
	Depression (β = -0.09, SE=0.05)	Anxiety* (β = 0.09, SE= 0.04)	Negative partner* (β= -0.12, SE= 0.04)
	Physical health* (β = -0.02, SE= 0.01)	Previously smoke (β = 0.25, SE= 0.18)	Physical health* (β = -0.02, SE= 0.01)
	No. comorbid* (β = 0.14, SE 0.06)	Currently smoke* (β = 0.72, SE= 0.36)	No. comorbid* (β = 0.23, SE= 0.08)
		Physical health** (β = -0.03, SE= 0.01)	
		Abstain alcohol* (β = 0.55, SE= 0.24)	
		Harmful alcohol (β = -1.02, SE= 0.61)	
	Block 1= 10.479**	Block 1= 8.183*	Block 1= 14.541*
	Block 2= -1.201	Block 2= 1.230	Block 2= 0.00
	Block 3= 28.562**	Block 3= 36.295**	Block 3= 18.450**
MCD	Positive friend* (β = 0.48, SE= 0.48)	Positive friend (β = 0.34, SE= 0.26)	Positive friend* (β = 0.56, SE= 0.24)
	Negative friend* (β = -0.57, SE= -0.57)	Mastery* (β = -0.20, SE = 0.10)	Negative friend * (β = -0.40, SE= 0.19)
	Negative family* (β = 0.45, SE= 0.15)	No. comorbid** (β = 0.73, SE= 0.21)	Mastery* (β = -0.18, SE= 0.09)
	Mastery* (β = -0.19, SE= 0.08)		Health insurance (β = -1.01, SE= 0.55)
	Fully responsible household tasks* (β =1.02, SE= 0.52)		Moderate exercise* (β = -1.27, SE= 0.64)
	Not at all responsible household tasks (β =-0.98, SE= 0.66)		Vigorous exercise (β = -1.39, SE= 0.86)
	Depression* (β = -0.30, SE= 0.15)		
	No. comorbid (β = 0.29, SE= 0.16)		
	Block 1= 22.949*	Block 1= 8.871*	Block 1= 14.707*
	Block 2= -0.391	Block 2= 0.00	Block 2= 3.414
	Block 3= 6.143*	Block 3= 15.175**	Block
Dementia	Physical health* (β = -0.25, SE= 0.09)	Past smoker (β =2.74, SE= 1.51)	Positive family* (β =-1.14, SE= 0.45)
	Negative friend* (β =-1.19, SE= 0.56)	Currently smoke (β = -3.56, SE= 2.54)	Positive partner* (β =2.46, SE= 1.04)

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	Fully responsible household tasks (β = -3.79, SE= 1.68)	Physical health (β = -0.13, SE= 0.08)	Negative partner (β =0.35, SE= 0.19)
	Not at all responsible household tasks (β = -2.48, SE= 1.71)	Abstain alcohol (β = -22.00, SE= 8717.24)	
	Abstain alcohol* (β = -3.78, SE= 1.82)	No responsibility household tasks (β =-2.58, SE=1.78)	
	Past smoker* (β = 3.37, SE= 1.65)	Fully responsible financial management* (β =3.65, SE= 1.79)	
	Currently smoke (β = -1.75, SE= 2.81)	No responsibility financial management (β =2.41, SE= 2.05)	
	Moderate exercise* (β = -5.89, SE= 2.20)	Live alone (β =16.97, SE= 8889.24)	
		Health insurance* (β =-3.46, SE= 1.53)	
		Moderate exercise* (β =-5.02, SE= 1.95)	
	Block 1= 7.487	Block 1= 13.677*	Block 1= 17.442*
	Block 2= -1.789	Block 2= 3.441	Block 2= 0.00
	Block 3=38.937**	Block 3= 19.183*	Block 3= 0.00

Note: SE= standard error, MCD= mild cognitive disorder. *p<.05, **p<.001.

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Table 3. Results of negative binomial GEE model for length of stay, significant variables only

Variable	β, SE
Dementia	β = 0.66, 0.18**
MCD	β = -0.46, 0.14*
Education	β = -0.11, 0.02**
No. comorbid	β = 0.11, 0.03**
Male	β = 0-.85, 0.10**
Physical health	β = -0.05, 0.01**
Household tasks (0%)	β = -0.60, 0.12**
Household tasks (100%)	β = 0.59, 0.11**
Financial management (0%)	β = 0.66, 0.12**
Financial management (100%)	β = 0.23, 0.11*
Financial problems	β = -0.49, 0.16*
Lives alone	β = 0.60, 0.14**
Married	β = 0.98, 0.14**
Vigorous Exercise	β = 0.39, 0.12*
Moderate exercise	β = -0.50, 0.09**
Friend negative	β = 0.08, 0.03*
Family positive	β = -0.14, 0.04*
Family negative	β = 0.06, 0.03*
Partner positive	β = 0.02, 0.01**
Age	β = -0.15, 0.03*
Anxiety	β = 0.06, 0.02*
Depression	B= -0.09, 0.03*

Note: MCD= mild cognitive disorder, SE= standard error, *$p<.05$,**$p<.001$
**$p<.001$

7.3 Summary

Paper 5 examined the different factors which could contribute to use of healthcare services, based on the Andersen-Newman model. It found that dementia increased the number of overnight hospital admissions and the length of hospital stay. MCD increased the number of same day admissions but decreased the length of hospital stay. Different factors contributed to usage of hospital services (ED presentation, same day and overnight admissions) depending on whether individuals were cognitively healthy, had MCD or dementia. For example, physical health was significantly associated with all three hospital services in cognitively healthy individuals. However, physical health was only associated with ED use for dementia participants. Predisposing and need variables explained the majority of each individual's use, with health insurance only significant for use of overnight hospital admissions by dementia participants.

Studies which have examined the impact of cognition on healthcare service use have examined people with dementia (Forbes et al., 2006; Toseland et al., 2002), used nursing homes residents for their sample (LaMantia et al., 2016; Stephens et al., 2014) or had methodological flaws. For example, a number of studies have only used the MMSE, or an adaptation of it, rather than a neuropsychological assessment (Korten et al., 1998; Redondo-Sendino, Guallar-Castillón, Banegas, & Rodríguez-Artalejo, 2006; St-Hilaire et al., 2017; Zimmer et al., 2001). Although the MMSE is used for screening for cognitive impairment it is not sensitive to subtle cognitive decline (St-Hilaire et al., 2017). However, it is important to examine people with MCI/MCD as they are at a higher risk of remaining cognitively impaired or progressing to dementia.

Gaining an understanding of the reasons why older adults use health care services and opportunities for interventions is essential for planning informed strategies to meet the health care needs of an ageing population (Gruneir, Silver, & Rochon, 2011). For example, in this paper positive family support was shown to decrease same day admissions in dementia participants. This association may be due to family members providing services or care which decreases the risk of

individuals being hospitalised. Providing support to an individual with dementia can be burdensome and carers may use more health services as a result (Bremer et al., 2015). Therefore, to sustain positive support, future programs and policies need to provide support services for these family members.

Another example relates to affordability of services. Not having health insurance and being on a pension-only income decreased visits to a GP. However, neither of these variables was associated with ED presentations. Instead of going to a GP, a fee-paying service which may result in follow-up consultations, individuals may go to an ED, thereby increasing ED presentations. Ensuring that access to primary health care is affordable, especially for individuals with a cognitive impairment, is important now and in the future.

This chapter has discussed the different factors associated with GP visits, ED presentations, overnight and same day hospital admissions and length of hospital stay and how these differ for individuals with Dementia, MCD or those who are cognitively healthy. The next chapter will discuss the policy implications of healthcare service research, including primary, secondary and tertiary prevention.

Chapter 8: HEALTH SERVICE USE AND IMPLICATIONS FOR POLICY AND PRACTICE

8.1 Introduction

The previous three chapters have discussed the association between cognitive decline or impairment and use of three types of health services, GP, hospital and ED. This chapter discusses the implications of these research findings for policy and practice, including screening and detection of cognitive impairment in GPs, EDs and hospitals.

Previous research and government reports emphasise the impact that increases in the prevalence of dementia will have on demand for health services. However, the previous three chapters have examined cognitive impairment and cognitive decline in a cohort study and found that even mild declines in cognition are associated with an increased demand. These research findings are important and have implications for policy and future prevention strategies.

Given that the demand on health services is exacerbated by increases in the prevalence of cognitive impairment we need to ensure that the services provided, existing and future, are suitable for the changing population. As the diagnosis and management of MCI improves we will also need to evaluate and reorganise existing services or develop new services for people with MCI and their carers. To ensure that health services will be able to meet this increased demand, or even reduce this demand, policy makers could develop innovative policies and programs over the three categories of prevention- primary, secondary and tertiary. These policies or programs need to be based on quality evidence to ensure that they are successful. Different strategies as they relate to each of these categories are discussed in detail below.

8.2 Primary Prevention

Given the association between cognitive impairment and increased use of health services, strategies for primary prevention of MCI and dementia are likely to reduce incidence, resulting in a decrease in future demand on health services. The National Dementia Research and Translation Priority framework (NHMRC, 2015) has assigned prevention as one of its key outcomes. Actions to achieve this outcome include population-level health strategies and effective interventions to reduce the risk and lower the incidence of dementia, including increased understanding of biomarkers and the Australian population's risk factors. Research into risk and preventative factors may have an impact on reducing the incidence of MCI and dementia if it is effectively communicated to policy makers and practitioners. Strategies for optimising research on prevention include improvements in data sharing and linkage, establishing nation-wide longitudinal studies covering a broad population cohort and coordination with international research (NHMRC, 2015).

Increased rates of MCI and dementia could be prevented through the modification of lifestyle-related risk factors, such as tobacco use, unhealthy diet, physical inactivity or harmful alcohol use. The overlap between risk factors for dementia and risk factors for lifestyle-related chronic diseases suggests that there are benefits to taking a multi-disease approach to addressing these risk factors with the expectation of better population health overall (Cooper, O'Donnell, Atkinson, & Wilson, 2015). Experts have agreed that preventative health interventions may reduce the incidence of dementia and recommend that health promotion strategies for reducing risk need to be implemented now (Farrow, 2010).

Changes to health policies and services could impact on the modification of dementia risk factors. These might include the development and implementation of health promotion campaigns that stress the benefits of participation in appropriate health behaviours and leisure activities or training health professionals to monitor health and vascular risk factors and provide adequate information and guidelines regarding prevention and consequences (Werner & Korczyn, 2008).

Australia would benefit from development of a national dementia prevention policy that fits within our healthcare system and includes education, resource development and targeted interventions (Farrow, 2010). A national dementia prevention policy could be integrated into policies and strategies for general preventative health. Elements of such a policy might include education for the general community and primary health care providers; integration of preventative health practice into existing primary health care systems and processes; and assessment and implementation of the infrastructure required to support dementia prevention programs. This policy could also include public health programs that provide the resources required for people to change their behaviour and to evaluate their outcomes; public health programs that reach at risk people in the community and cooperation with preventative health approaches to other chronic diseases. By highlighting the importance of modifying dementia risk factors in the population this policy may also increase research into the risk and preventative factors associated with cognitive impairment and the flexibility to incorporate new research as it becomes available (Farrow, 2010; NHMRC, 2015)

Evidence suggests that prevention activities work best with a combination of universal and targeted approaches, and with multiple strategies and interventions. For example, to reduce tobacco smoking government has relied on universal approaches incorporating restrictions on the promotion and sale of tobacco and public education programs and support to those quitting smoking. It has also relied on selective prevention approaches that targeted at-risk populations such as pregnant women and Indigenous Australians. For prevention strategies to be effective they require an enabling infrastructure that involves research, information, monitoring and evaluation over a long period of time (Australian Institute of Health and Welfare, 2014).

8.3 Secondary Prevention

Policies for secondary prevention, which is concerned with diagnosing and treating conditions early, could also reduce future demand on health services. A priority area for action in the National

Framework for Action on Dementia 2015 to 2019 is the need for timely and accurate diagnosis. This thesis has found that people with cognitive impairment visit a GP, are admitted to hospital and present to an ED more than those who are cognitively healthy. Increased exposure to these services provides an opportunity for early diagnosis in these individuals.

Strategies to achieve timely diagnosis can be divided into four areas: patient and care strategies, strategies to better support GPs at the service level; system change; and reduction of stigma surrounding dementia. Some of the strategies in these areas include public awareness campaigns to increase awareness of dementia and reduce the stigma of the disease, incentives for GPs to spend more time in the assessment process, training and education for GPs and including dementia in national health promotion activities and making the link between physical and brain health (Phillips et al., 2012).

The medical and public consensus is that diagnosis of dementia should be made as early as possible. Evidence suggests that it is during the early phase of dementia that both pharmacological and nonpharmacological treatments are likely to have maximum effect (Milne, 2010). Despite advances in the detection of dementia at an early stage, the ethics of when or indeed whether to diagnose dementia remains difficult. Some believe that early diagnosis is of little benefit. Screening is the first stage in the identification of MCI and dementia (Milne, 2010), however, the case for general population screening for MCI and dementia remains controversial (Jackson, Naqvi, & Sheehan, 2013). When deciding whether a population screening program is necessary, traditional decision-making would typically address the relative need for a screening program. This assessment would be influenced largely by internal and external contextual factors including political extra-jurisdictional factors (e.g. do similar programs exist in other jurisdictions?) and disease-specific characteristics (e.g. which population groups would be most affected by a population-wide program?). Other factors include the availability and reliability (specificity and sensitivity) of a screening test, cost-benefit analysis and ethical considerations, including the availability of effective

interventions (Dobrow, Goel, & Upshur, 2004). The possible harms and benefits associated with population screening and the process of screening and diagnosis in GP offices, emergency department and hospitals are discussed below.

8.3.1 Potential Harms of Population Screening

There are a number of potential ethical issues or harms of population-level screening of patients for MCI or dementia. Firstly, there is a potentially high rate of false positive in screening for cognitive impairment, especially when changes in cognition, including MCI, may be hard to detect and screening tools are not sufficiently sensitive or specific enough to establish a diagnosis (Phillips et al., 2012; Pottie et al., 2016). False positive results may result in high costs to the individual as they may be referred for further testing. It may also cause psychological and financial distress to the individuals, and reduce trust in their GPs judgement and competence (Iliffe et al., 2009). Conversely, a person may perform well on a screening test despite the presence of cognitive problems (a false negative). False negative results may lead to delays in diagnosis and treatment (Bradford, Kunik, Schulz, Williams, & Singh, 2009). An individual's performance on screening tests could be affected by practice effects, stress, fatigue or anxiety rather than declines in cognition. As such, the interpretation of these screening tests needs to be considered in the context of the person's presentation and behaviour in the assessment (Phillips et al., 2012).

The second harm is that the diagnosis of MCI may increase anxiety and/or depression in the patient, which may negatively impact on their prognosis, rather than be beneficial (Brodaty, Low, Gibson, & Burns, 2006; Chertkow et al., 2008). Patients diagnosed with cognitive impairment may fear negative financial or negative social consequences due to stigma (Boustani et al., 2003; Hansen, Hughes, Routley, & Robinson, 2008). Early detection of cognitive impairment can result in restriction of the patient's activities, preoccupation with the diagnosis or prognosis and hyper vigilance from family or carers. Family members may gradually take over the role and duties of the patient (Iliffe et al., 2009) and patients may foresee loss of autonomy and quality of life (Ganguli et al., 2004). The

diagnosis of cognitive impairment may also result in attributing changes in behaviour or cognition as another symptom of cognitive impairment when it may be due to another condition, such as depression (Iliffe et al., 2009) or drug side effects (Downs, 1996). Given the unsettled prognosis of MCI, with some individuals reverting back to normal cognition, these social and psychological harms resulting from screening may be unnecessary (Dale, Hougham, Hill, & Sachs, 2006). Thirdly, there may be harm to the society as a whole. This includes the financial costs and long-term service demands of providing screening programs and treatment regimes (Brodaty et al., 1998). Although early diagnosis of dementia may result in lower formal service costs, it may result in an increase in community-based service costs (Werner & Korczyn, 2008).

The WHO specifies that to meet criteria for screening there should be an accepted and established treatment or interventions and these should be available. Currently there is no pharmacological treatment for dementia or MCI which has shown to be effective and non-pharmacological therapies produce only small benefit which are not clinically significant (Petersen, 2011). As MCI is an unstable condition and individuals may revert back to normal cognition, ways to improve cognition, such as through pharmacological or non-pharmacological treatment, need to be further researched and applied. The lack of clinically accepted treatment may contribute to the reason why doctors are hesitant to screen for cognitive impairment (Hansen et al., 2008) and it may be considered harmful or unethical to screen individuals for a condition when there is no effective intervention available (Ganguli et al., 2004).

8.3.2 Potential Benefits of Population Screening

Most of the previous research indicates that screening is well accepted by patients and that the benefits of routine screening outweigh the potential harms (Borson et al., 2013). A study by Dale et al. (2006) found that 98% of participants would be willing to be tested for MCI if a family member suggested that they were having memory problems, 80% would want testing for MCI as a routine part of a medical examination and 83% would be willing to see their doctor about MCI.

One of the largest benefits of population screening for cognitive impairment in older patients is that early diagnosis and management may delay the onset of dementia or slow the rate of decline. This may be especially important for people with a family history of dementia or with multiple risk factors. There may be potentially reversible factors that are contributing to the patients MCI, such as depression, adverse effects to medication or alcohol dependence syndrome (Kaduszkiewicz et al., 2010; Rafii & Galasko, 2008). Individuals who are diagnosed as a result of screening may be better able to manage other health conditions that adversely impact their cognitive functioning and identify strategies to compensate for their memory loss (Rafii & Galasko, 2008). Failure to recognise and diagnose cognitive impairment not only deprives patients of the opportunity to make changes but may also lead them to a more limited and unhappy existence (McCarten, 2013).

Another benefit is that it allows individuals diagnosed with early stage dementia to plan for future needs (Hansen et al., 2008; Kaduszkiewicz et al., 2010). Depending on their prognosis and other risk factors, such as age or comorbid conditions, patients may re-evaluate financial issues and housing requirements, for example they may specify end of life care, appoint an Enduring Power of Attorney or relocate closer to people who could care for them (Boustani et al., 2003; Ganguli et al., 2004). Patients and their families can access appropriate resources and support services if MCI or dementia is diagnosed early (Prince et al., 2016). Even if individuals are not diagnosed with cognitive impairment, screening may motivate individuals to change health behaviours associated with developing dementia (McCarten, 2013). For example, they may try to give up smoking or become more physically active.

Finally, the costs of not detecting cognitive impairment may be higher than the costs of population screening. Patients whose cognitive impairment is not detected may have more preventable complications, hospitalisations and accidents than those whose cognitive impairment is detected (Brodaty et al., 1998). The likelihood of mismanaging medications or finances, or having an accident while at work, using tools or driving, or developing poor health habits increases as the

patient becomes more cognitively impaired (McCarten, 2013). Early detection and management of cognitive impairment and other conditions may result in lower hospital admissions, emergency department visits and long-term care service needs resulting in an economic benefit to the community as there will be lower cost to formal health services (Comas-Herrera, Wittenberg, Pickard, & Knapp, 2007; Saito, Nakamoto, Mendez, Mehta, & McMurtray, 2014).

8.3.3 Screening and Diagnosis in Primary Care

Primary care doctors are the best choice for screening older people for cognitive impairment as they are local, they are accessible, they usually have a relationship with their patients and they are trusted (Brodaty et al., 1998). However, cognitive impairment is currently under-detected, under-diagnosed, under-disclosed, under-treated and under-managed in primary care practices (Holsinger et al., 2012; Prince et al., 2016). Cognitive impairment is unrecognized in approximately 27-81% of affected patients in primary care in America (Cordell et al., 2013). Research has generally found that GPs have difficulty identifying patients with MCI, with approximately half of MCI or mild dementia cases remaining undetected, and are also poor at recording such diagnoses in medical records (Chodosh et al., 2004a; Mitchell, Meader, & Pentzek, 2011). For example, a systematic review of 12 studies, conducted mainly in Europe and North America, found that the number of cases not detected by primary care practitioners was 18.8% for moderate to severe dementia and 54.9% for mild dementia, with approximately only 37.9% of diagnoses recorded in patient notes (Prince et al., 2016).

Cognitive impairment may go undiagnosed when cases are complex, for example when the patients have multiple comorbid conditions (Iliffe et al., 2009; Mitchell et al., 2011). As the findings from this thesis have shown (Chapter 5, 6 and 7) individuals with cognitive impairment will use significantly more health services if they have other comorbid conditions or worse physical health. These individuals may visit their GP for these other medical problems rather than their cognitive problems (Olafsdóttir et al., 2000). This may decrease the likelihood of the GP detecting any

cognitive impairment as they might focus on the condition being presented (Ganguli et al., 2004; Olafsdóttir et al., 2000).

Detection and diagnosis or cognitive impairment could be improved by routine screening for cognitive impairment in the primary care setting using a standardised screening tool. However, routine or population, screening for cognitive impairment is not considered clinically- or cost-effective (Iliffe et al., 2009). One study reported that only 39% of GPs in Australia routinely screened for cognitive impairment in elderly patients (Brodaty et al., 2006). A previous study found that the most frequently cited reasons physicians do not favour routine screening for cognitive impairment were screening inaccuracy (44%), costs too much (33%) and lack of treatment (24%)(Bond & Corner, 2001). Issues related to cost include the cost of the tool, the time the GP spends with the patient administering the test and the cost of training the GP (Brodaty et al., 1998). Routine screening is not cost-effective as it would have to be applied to a large-scale group that is at low risk of cognitive impairment in absolute terms (Iliffe et al., 2009; Stewart, 2012).

Another problem is that there is no standardised screening tool for cognitive impairment. In the primary care setting the ideal cognitive screening tool would be brief, easily administered, easily memorised and scored, and have high sensitivity and specificity for identifying impairment (Holsinger et al., 2012). Using a brief, structured cognitive assessment tool correctly classifies patients with MCI or dementia about 83% of the time, whereas the spontaneous detection by the patient's GP classifies them correctly about 59% of the time (Cordell et al., 2013). The lack of explicit advice about which instrument to employ is problematic (Milne et al., 2008). Until 2001 there was no specific cognitive screening tool to detect MCI (Chertkow et al., 2007). Now there are over 100 brief cognitive assessment tools that primary care physicians can use to detect cognitive impairment (Cordell et al., 2013). This may result in variances in prevalence and incidence of cognitive impairment, or problems in the diagnosis of MCI. The three brief cognitive assessments which have been recognised in the literature as being the most suitable or used in the primary care setting are

the Memory Impairment Screen (MIS), the General Practitioner Assessment of cognition (GPCOG) and the mini-cog (Cordell et al., 2013).

Primary care physicians can use a brief screening tool to detect cognitive impairment, however, diagnosis in primary care is not that simple. The diagnosis of cognitive impairment is a long process, requiring GPs to monitor patients over a long period of time (Hansen et al., 2008). Results of a screening test should be interpreted in the context of other information about the patients as it may partly or completely explain the result (Brodaty et al., 1998). For example, if the patient is overmedicating, has psychosis or has a poor education then these factors may be affecting their result. One study found that patients with MCI with a middle or high level of education got a false negative result more than patients with a low education level and that the risk of false positive result increased the more comorbid conditions the patient had (Kaduszkiewicz et al., 2010). Incorrectly diagnosing a range of behaviours as cognitive impairment may create the potential for under-treatment of manageable conditions and misdirects patients to inappropriate specialist services (Milne, 2010).

Given that population screening is not currently advocated, it is suggested that a case-finding approach to detection of dementia or MCI, or indicated screening, could be used to achieve timely diagnosis (Prince et al., 2016). Case-finding means that the patients present with, or the caregiver reports, symptoms suggestive of dementia (Phillips et al., 2012). Patients with a high risk of cognitive impairment, such as those with first degree relatives of patients with dementia may benefit from regular testing and could be an appropriate starting sample for eventual larger-scale screening programs (Mitchell & Black, 2016). GPs should still be alert to early signs and symptoms of cognitive impairment (Moyer & U. S. Preventive Services Task Force, 2014). Recognition of MCI or dementia in primary care could be boosted by education, training and access to recent, relevant research (NHMRC, 2015; Prince et al., 2016). Access to an online dementia pathway tool, comprising a

decision tree and associated information, could also assist GPs and with diagnosis, referral and care planning for all stages of dementia (Ollerenshaw et al., 2018).

8.3.4 Screening and Detection in Hospital and Emergency Departments

It is important that cognitive impairment is detected and managed when elderly adults present to the emergency department or are admitted to hospital. As paper 4 (Chapter 6) demonstrated individuals with cognitive impairment may have more hospital admissions and longer stays, and hospitalisation is associated with decreases in cognitive functioning. Emergency departments are often the gateway to hospital admission for people with cognitive impairment and may be the last chance to prevent unnecessary hospitalisation (Prince et al., 2016).

Although there has been a detailed debate about screening for cognitive impairment in primary care and community settings, there has not been one about the advantages and disadvantages of screening in general hospitals and emergency departments (Shenkin, Russ, Ryan, & MacLullich, 2014) or whether early detection is followed by appropriate actions that actually improve the patients' situation (Aminzadeh & Dalziel, 2002; Hessler et al., 2017). There are many benefits of completing a baseline cognitive screen, and if necessary a validated delirium screening tool, in hospital and emergency departments (Australian Commission on Safety and Quality in Health Care, 2018).

Firstly, cognitive screening provides an important opportunity to detect cognitive impairment and/or delirium in elderly patients and provides the possibility for early intervention and treatment (Boustani et al., 2010; Woon, Dunn, & Hopkins, 2012). This is important from a public health perspective as it could help detect subjects who are at risk of medical injuries which usually increase the length of hospital stay as well as the cost of hospitalisation (Mecocci et al., 2005). Early detection of cognitive impairment and/or delirium may therefore reduce health care costs because it results in less aggressive and less costly treatment (Gerson, Counsell, Fontanarosa, & Smucker, 1994; Hare, Arendts, Wynaden, & Leslie, 2014).

Secondly, in the hospital setting it is important that doctors are aware of their patients cognitive function so they can manage safety and quality risks, reduce adverse events such as falls, dehydration, incontinence, loss of mobility and pressure injuries, improve the healthcare outcomes for older patients during and after a hospital stay and not prescribe medications that contribute to further declines in cognition (Boustani et al., 2010; Tuijl, Scholte, Craen, & Mast, 2012).

Thirdly, cognitive impairment in hospital is associated with nursing home admission at discharge. Screening for cognitive impairment at admission to hospital may facilitate interventions to prevent nursing home admission and other adverse outcomes (Joray et al., 2004). Finally, screening tools provide a more accurate indication of cognitive impairment and delirium than clinical judgement. These screening scores can provide a baseline to compare any further testing undertaken during the current and any subsequent hospital stays (Hare, Wynaden, McGowan, & Speed, 2008; Hare et al., 2014; Tomlinson, 2016).

Despite the benefits of screening in hospitals and emergency department cognitive impairment and delirium is under-recognised in current assessment practices (Australian Commission on Safety and Quality in Health Care, 2018). For example, studies have found that cognitive impairment has not been detected in 37%-61% of elderly hospital patients (Boustani et al., 2010; Joray et al., 2004). The reasons why cognitive impairment is not detected in a proportion of hospital and ED patients are similar to those of screening in primary care- there is no routine screening, medical and nursing staff are more focused on treatment and management of presenting diseases, and cognitive assessment is rarely completed because of clinical and time constraints (Aminzadeh & Dalziel, 2002; Mathews et al., 2013; Mecocci et al., 2005; Yevchak et al., 2015).

Identification of subtle cognitive deficits can be a challenge as many individuals with cognitive impairment, especially in the early stage, may have intact language and memory and be perceived as functionally independent (Buslovich & Kennedy, 2012). Similar to primary care the type of screening tool used for detecting cognitive impairment in emergency departments or hospitals and the way it

is administered and interpreted require careful consideration. Poor scoring on a single cognitive test may indicate the presence of dementia and/or delirium but it may also be due a range of other reasons such as acute illness, pain, lethargy, medications (e.g. opioids, benzodiazepines), depression, anxiety, sleep disturbance or the effect of other uncontrolled comorbid disease such as diabetes (Russ et al., 2012; Shenkin et al., 2014). Poor scores could simply reflect not understanding the questions due to language, health literacy or cultural barriers, not wishing to engage with testing or to hearing impairment or learning difficulties.

As with screening in primary care, detection of cognitive impairment in hospital could have potentially harmful consequences, including false positives, financial trauma and the emotional impact of a diagnosis with limited treatment options (Hessler et al., 2017). Given these potential harms identification of cognitive impairment during hospital admission needs to lead to a dementia friendly pathway that includes staff awareness, attention to the physical environment and better communication with primary care (NHMRC, 2015).

8.4 Tertiary Prevention

Along with primary and secondary prevention, policies and programs could be developed for tertiary prevention of dementia. Tertiary prevention seeks to soften the impact caused by the disease on the patient's function, longevity, and quality of life, and promote patients' adjustment to chronic or permanent conditions, for example by preventing complications (Royal Australian College of General Practitioners Ltd). Two of the key domains of the National Priority Framework (NHMRC, 2015) are living with dementia and care. These domains require that the dignity, independence and self-determination of people living with dementia are supported and that high quality of care and quality of life are established.

When people with dementia are admitted to hospital or present to ED there is a tension between addressing the cause for admission (task-centred acute care) and the need to provide person-centred dementia care (Prince et al., 2016). To minimise potential risks of harms and provide

care that is aligned with their preferences and is medically appropriate for their circumstances, patients with cognitive impairment should receive person-centred, goal-directed care. Care for people with dementia in hospital needs to take into consideration the stage of their dementia. For example, a wide range of therapeutic interventions should be available to individuals with MCI or early stage dementia who live at home and are independent in most activities of daily living. However, the use of many therapeutic options for individuals who have end-stage dementia, who may be bed-bound, have very limited or no vocabulary and experiencing episodes of aspiration or dehydration due to poor oral intake, is ineffective (Caplan et al., 2016). Modifying aspects of the nursing work environment, such as having a mix of staffing skills and measuring staff workload, may also reduce or prevent complications in hospitalised dementia patients (Bail et al., 2013).

The Australian Commission on Safety and Quality in Health Care has released a set of resources for clinicians, health service managers and consumers to improve the early recognition of, and response to, patients with cognitive impairment so that they receive safe and high quality care (Caplan et al., 2016). Several programs have been designed to improve the care of patients with dementia from the moment they are admitted to hospital to when they are discharged. One of these programs is the "Dementia-Friendly Hospitals: Care Not Crisis." This education program provides information and resources to nurses and other direct-care staff (e.g. physical therapists, discharge planners and social workers) to improve the care of hospitalized patients with dementia (Galvin et al., 2010). Another education program is the "Dementia Care in Hospitals Program". This program is designed to improve communication with and awareness of patients with cognitive impairment and is linked to a bedside alert, called the Cognitive Impairment Identifier (CII). The program involves a targeted training program for hospital staff to ensure that when a CII is displayed all staff will respond appropriately and provide more person-centred and responsive care (Ballarat Health Services, 2017). The Dementia Care in Hospitals Program was implemented in the Canberra Hospital in June 2015 (ACT Health Directorate, 2017). The Hospital Dementia Services project explores how hospital-based aged care and dementia services influence hospital outcomes for people with

dementia in New South Wales, Australia. The project found that acute general hospitals have limited resource and health services for people with dementia. Efforts to improve the care of dementia patients in acute hospitals, such as staff education, standardised care protocols, environmental modification and involvement of skilled experts, is required. The project found strong evidence that integrated hospital and community services are effective for providing physical and mental health service services in aged care (Draper et al., 2014).

Chapter 2 of this thesis discussed factors in the hospital environment that may increase an individual's risk of cognitive dysfunction, such as sleep deprivation, medication use and presence of delirium. The development of Hospital in the Home services has provided clinicians with the opportunity to provide treatment to individuals without exposing them to the hospital environment long-term. There is evidence that Hospital in the Home is associated with lower incidence of delirium, mortality and cognitive and physical dysfunction. Given this evidence, if suitable treatment can be provided at home as an alternative to hospitalisation than it should be the recommended choice to older patients (Caplan, 2008; Caplan et al., 2016; Caplan et al., 2012).

In addition to interventions aimed at improving the quality of care for older people with cognitive impairment, practical strategies and actions are needed to manage the increasing demand on GP, ED and hospital services (Lowthian et al., 2011). Interventions aimed at strengthening primary care services for people with cognitive impairment include establishing walk-in centres (nurse-led services handling low acuity presentations), community centres or an emergency nurse in residential care units (Van den Heede & Van de Voorde, 2016). As the diagnosis of MCI becomes more advanced existing services need to be reorganised and/or new services need to be developed for patients with MCI and their relatives. The government could consider the use of support groups for people with MCI. Such groups are useful against the effects of stigmatization on the individual, and may include the provision of information regarding MCI and its progression, as well as

information regarding life style changes associated with secondary prevention in persons with MCI such as physical activity and nutrition (Werner & Korczyn, 2008).

The special needs of hospitalised older adults with cognitive impairment have been shown to increase demands on nursing staff, risk of post-discharge hospitalization, length of stay and health care costs (Boustani et al., 2010). Excess utilisation of hospital and ED services often results from complications in coexisting conditions caused by dementia, care management problems and lack of care coordination (Bass et al., 2015). Actions from primary and secondary prevention, such as health promotion campaigns aimed at reducing chronic conditions or screening and management of chronic diseases and in primary care to avoid complications, could reduce the need for ED services and rate of hospitalisations (van den Berg, van Loenen, & Westert, 2016; Van den Heede & Van de Voorde, 2016).

Excess utilisation of hospitals and EDs may also be due to lack of care alternatives during crisis, insufficient family support and unmet need for home and community services (Bass et al., 2015). For example, paper 5 in this thesis (Chapter 7) found that quality of social support was significantly associated with hospital admissions and ED presentations. Other studies argue that limited access to a GP is one reason a patient may attend an ED. Some ED users have an illness that could have been treated by a GP, with the rate of inappropriate ED presentations being 20% to 40% internationally (van den Berg et al., 2016). It is also possible that GPs consultation fees may have an impact on level of use, as there are no out-of-pocket expenses for ED consultations (Lowthian et al., 2011; van den Berg et al., 2016).

A number of intervention programs aimed at reducing ED and hospital visits have been designed. These include referral interventions for ED (Karam et al., 2015); care coordination interventions, such as case-management, individual care planning, post-discharge telephone calls and relational continuity of care (Bass et al., 2015; Van den Heede & Van de Voorde, 2016); and educational interventions (Van den Heede & Van de Voorde, 2016). Of all these intervention

programs the integrated model of care seems to result in the greatest benefits to patients. Integrated models of care are high intensity interventions which appear to be better able to meet the needs of older adults as they integrate older adult services, increase access to community-based serviced and reduce ED visits and nursing home admissions by 10% (Karam et al., 2015).

As the older proportion of the population continues to rise, there will be a persisting increase in demand for primary care services, emergency care and hospital admissions unless initiatives are put in place. Identification of the underlying causes for increased demand of these services by older people could help to target the planning of appropriate models of care for this age group (Lowthian et al., 2011).

8.5 Summary

This chapter has discussed the implications of our research findings for policy and practice. More research on how GP and hospital use is associated with cognitive impairment is required. In order to improve prevention programs there needs to be more information on risk factors and how these can impact on health service use in individuals with cognitive impairment. Future research could also examine the practices related to hospitalisation that increase risk or risk factors of cognitive impairment, and if appropriate, consideration be given to minimising their use in patients at risk of cognitive impairment. For example, more information is required on medications and surgery that may increase risk of cognitive impairment. These future research findings need to be effectively communicated to policy makers and practitioners to develop and implement strategies for future need.

Given the expected rise in dementia due to population ageing it is important that the government implement primary preventative strategies, such as health promotion campaigns and policies aimed at eliminating lifestyle risk factors, to curtail the incidence of dementia. The largest

concern for secondary prevention of dementia is timely diagnosis. Within this chapter we discussed the potential harms and benefits of screening and the screening and detection of cognitive impairment in primary care, hospitals and emergency departments.

This chapter finished with a discussion on tertiary prevention of dementia. Tertiary prevention aims at ensuring that dementia patients are being provided with quality care, and ensuring that strategies are in place to meet future demand, for example by reducing the level of ED presentation and hospital admissions through intervention programs. The next, and final, chapter of this thesis will provide a summary of the research provided in this thesis, future research directions and conclusions.

Chapter 9: CONCLUSION AND FUTURE DIRECTIONS

As stated in the introduction, this thesis has two main aims. The first aim is to investigate the association between cognitive impairment and the use of three health services- general practitioners, hospital admissions and emergency department presentations. In chapter four I presented a published paper on the general practitioner use between individuals with MCD and those who were cognitively healthy. The use of healthcare services was then further examined in chapter five where I presented a paper on the association between hospitalisation and cognitive impairment. Chapter six than analysed which factors, based on the Andersen Newman Model, predicted the use of the three health services (general practitioners, hospitals and emergency departments).

The second aim of this thesis is to examine the policy implications of the research findings and critically analyse the process of translating research into policy. This is achieved in chapter four of this thesis which discussed knowledge translation. This chapter examined the models and frameworks of knowledge translation, the barriers to and enablers of knowledge translation and made recommendations for both policy makers and researchers of ways to effectively translate research into policy. As part of this thesis the author undertook a secondment in a health-related government policy department to understand the complexities of the policy making process and the dissemination of academic research to policy makers. The findings from this secondment are presented in a published paper in chapter four.

Chapter eight provides a critical analysis of the policy implications of the research findings presented in chapters five, six and seven. These implications included prevention strategies to reduce the rate of dementia, the benefits and harms of screening for cognitive impairment, and strategies to ensure the provision of appropriate services for patients with MCI or dementia in future. The research findings and implications presented in this thesis demonstrate that the quality of life for people with cognitive impairment, particularly dementia, is unlikely to improve unless

there is a higher profile in health policy for issues such as prevention, early diagnosis and safer

hospitals (Skladzien, Bowditch, & Rees, 2011).

This thesis has demonstrated that older individuals experiencing cognitive impairment use more

health services than those without any impairment. To examine the association between health

service use and cognitive impairment this thesis used four large, longitudinal datasets linked

together. The use of large datasets, such as those used in this thesis, identifies gaps in existing

studies and answers critical questions about dementia risk and prevention (NHMRC, 2015). Linked

datasets enable patient pathways to be mapped on an individual level and provide an understanding

of how patients interact with the components of the health and aged care systems. Using linked

datasets for future research would provide more accurate information on the effectiveness and

appropriateness of the care older Australians receive (Australian Institute of Health and Welfare,

2016a).

The research and the findings presented in this thesis were designed to be applicable to the local

context, relevant to policy and practice, and provide guidance for future policy making and practice

actions. Although the findings in this thesis contribute to existing information on service use and

knowledge translation, further research is needed. More information on the determinants and use

of other health services, for example residential aged care, home based care and informal care, and

how these contribute to health service pathways of dementia patients would provide key data on

how to avoid unnecessary use of health services.

More research is needed with regards to primary, secondary and tertiary prevention of cognitive

impairment and the influence of policies and programs on reducing the incidence of dementia, use

of health services, increasing timely diagnosis and ensuring quality health care for dementia

patients. Analysis of service and system level interventions to strengthen primary care practice and

to avoid emergency department presentations and hospitalisations for patients with cognitive

impairment is also required (Prince et al., 2016).

As MCI individuals are at a higher risk of converting to dementia more research on screening for and treatment of MCI is also needed. There is a lack of evidence on the effect of screening and early detection of mild to moderate dementia on decision-making, planning and/or other important patient outcomes. More research on biomarkers and more understanding of the relationship between MCI and dementia is required. The findings from this research could strengthen our ability to identify which cases of MCI are at risk of converting to dementia. Research is also critically needed on new interventions to address the changing needs of patients and their families, interventions that will have a clear effect on the long-term clinical course of mild to moderate dementia and interventions that are effective in preventing the progression of cognitive decline (Moyer & U. S. Preventive Services Task Force, 2014).

Although several models and frameworks of knowledge translation have been conceptualised and the barriers and enablers of knowledge translation have been identified more work needs to be done on how to measure and evaluate knowledge translation actions. For example, before establishing a reciprocal secondment between organisations determine how 'success' will be measured and throughout the secondment ensure that all actions and outcomes of knowledge translation processes are documented. Given the 'two communities theory' it is recommended that the relationship between producers and users be strengthened and that each party 'walks in the others shoes' to build a mutual understanding of the other. By developing an understanding of the other policy makers may learn more about the research process and researchers may realise that scientific evidence is one of several factors considered, if at all, in the decision-making process.

This thesis has examined the use of health services in an elderly population, its association with cognitive impairment and the implications of these findings for policy makers. This study used large, linked datasets on community-dwelling older individuals living in the capital of Australia and found that even MCI can contribute to a higher usage of primary and secondary health services. It is important that the research findings in this thesis are communicated to policy and decision makers

as they have implications for the future of Australia's health services, including an increased demand for access and funding. The authors intend to communicate these findings in future using knowledge translation strategies.

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APPENDICES

Appendix A: Study Questionnaires

In-depth interview with Academic Epidemiologists

Epidemiologist views on the quality of evidence and evidence rating systems

Questions

1. Please briefly describe your educational background and your current working role:

2. In your opinion, what constitutes high quality observational research?

3. What is your view on the typical hierarchy of evidence and how research evidence is rated?

   (E.g. the strengths/weaknesses). *See Figure 1 for a typical example of the hierarchy.*
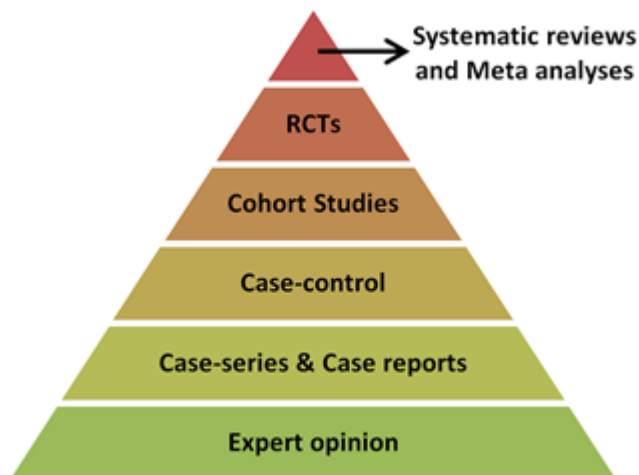
Figure 1. Typical hierarchy of evidence pyramid

4. Do you know anything about current rating systems for grading evidence? If yes, which systems have you heard of, and where are they used?

5. Do you use a specific rating system to evaluate research evidence in your own practice? If

yes, what is it? If no, how do you evaluate the quality of research evidence?

6. In your view what are the consequences/costs of inappropriate rating of observational

   research? Is it a concern and why?

Thank you very much for being a part of this research and contributing your time to better our

understanding of this aspect of knowledge translation

In-depth interview with Policy makers

Background Information

Participant ID:	**Role in Organisation**:
Age: 26-35, 36-45, 46-55, 56-65, 66+	**Time in Organisation**:
Gender:	**Length of career in policy**:
Interview Date:	**Education**:

Indicative Interview Guide

1. **Tell me about your role in the policy making process?** *(Gain thorough understanding of person's position and typical duties re policy making, frequency, level of responsibility etc.)*

2. **Could you walk me through a recent occasion when you were asked to contribute regarding a policy decision in an area that required the input of research evidence?** *(Gain an understanding of the process from start to finish, where the request originates, what are the external/internal influences, how many actors are typically involved and their roles, how is research accessed, how is research assessed, is this process the same-similar every time?)*

3. **What are your preferred sources of evidence?** *(Explain answer)* **Are the same sources the most useful and/or influential in policy discussions – if not, which ones are?**

4. **In your opinion, what does "high quality evidence" mean? What sources would you include under this definition and what provisos would you put on them?**

5. **What are the biggest obstacles or barriers when it comes to accessing and using research?**

6. **To what extent do you think research influences policy outcomes?** *(Explain answer – if little, what are the problems – if it varies, what are the reasons).*

7. **What factors do you think would make research more useful and/or accessible for policy makers?**

8. **What factors do you believe could make policy-makers more receptive to research?**

9. **Is there anything else you might want to add on this topic before we wrap up?**

Thank you for your time. Do you have any questions that you would like to ask of me?

Interview Schedule taken in part from: Hanney, S.R., Gonzalez-Block, M.A., Buxton, M.J., Kogan, M. (2003). The utilisation of health research in policy-making: concepts, examples and methods of assessment. *Health Research Policy and Systems 1*:2.

Quantitative Web-survey with Policy makers: **Bridging the Research to Policy Gap**

You have been asked to complete this web survey because of your role in developing or influencing government policy in the public health arena. Your responses to the questions in this survey will help us to better understand the role of research in policy, what some of the barriers are, and some of the competing influences. The survey should take only approximately 10 minutes to complete and will provide us with valuable data. We very much appreciate you taking the time to contribute to this important research. This survey is anonymous - responses are not linked to your identity. For more information on this research you can go to our website

Knowledge translation can be understood as, "*the synthesis, exchange, and application of knowledge by relevant stakeholders to accelerate the benefits of global and local innovation in strengthening health systems and improving people's health*" (World Health Organisation, 2005).

1. **As far as you are concerned, how significant are the barriers listed below to knowledge translation from research into policy in your current work environment?**

	Not at all significant	Slightly significant	Neutral	Quite significant	Extremely significant
Lack of communication with researchers					
Poor dissemination of research results				•	•
Mismatch between research aims and policy aims	•	•	•	•	•
Timing of research	•	•	•	•	•
Results not presented in way that's easily applicable to policy	•	•	•	•	•
Lack of resources (e.g. training, time, staff)	•	•	•	•	•
Budgetary constraints	•	•	•	•	•
Lack of access to evidence (e.g. via PubMed or library)	•	•	•	•	•
Political	•	•	•	•	•

agenda/influences					
Available evidence lacks local relevance	•	•	•	•	•
Other - please describe	•	•	•	•	•
Interference from lobby groups/industry	•	•	•	•	•
Disagreement from consumers	•	•	•	•	•

2. **In your view, knowledge translation is the responsibility of**:

• Knowledge producers (e.g. – researchers, research institutions) (1)

• Knowledge users (e.g. – policy makers, clinicians) (2)

• Knowledge translation professionals (e.g. knowledge brokers) (3)

• A combination of the above (4)

• Other - please describe (5) _____

3. **If you could ask researchers to undertake a study on an issue relevant to your area of work, what sort of study would you prefer and what would you want to find out? Please type in the text box below.**

4. **Have you used any ACT Health reports in formulating new policies? If so, which one(s)?**

- Yes (please indicate which ones you have used) (1) _____

- No (2)

5. **In your opinion, what constitutes high quality evidence?   Please type in the text box below.**

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[                                                    ]
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6. **Please give each of these types of research a "quality of evidence" rating, according to your understanding of quality evidence. On the right-hand side please also choose your preferred research method(s) when building an evidence base.**

	Quality of evidence rating				Your preferred research method(s)
	Low quality	Medium quality	High quality	Don't know	Click to select
Randomised Control Trials	•	•	•	•	•

Systematic Reviews	•	•	•	•	•
Observational research	•	•	•	•	•
Meta-analyses	•	•	•	•	•
Expert opinion (e.g. clinician)	•	•	•	•	•
Cohort studies	•	•	•	•	•
Case-control studies	•	•	•	•	•
Case-reports/case studies	•	•	•	•	•
Case-series	•	•	•	•	•
Government reports (e.g. ABS)	•	•	•	•	•
Qualitative research (e.g. interviews)	•	•	•	•	•
Other - please describe	•	•	•	•	•

7. **Please indicate how important each of the following are when you evaluate evidence that might contribute to policy:**

	Not at all Important	Unimportant	Medium Importance	Important	Extremely Important
Reputation of journal	•	•	•	•	•
Reputation of researcher or clinician	•	•	•	•	•
Consistency and strength of evidence	•	•	•	•	•
Type of evidence (e.g. observational study vs. randomised control trial)	•	•	•	•	•
Recency of evidence	•	•	•	•	•

The evidence is locally applicable	•	•	•	•	•
Quality of the data (whether it is a systematic review, or a large study vs. small poorly designed research)	•	•	•	•	•
Risk of bias in the evidence	•	•	•	•	•
The evidence 'backs up' the policy	•	•	•	•	•
Other - please describe	•	•	•	•	•

8. **When working on a policy development task: Please indicate HOW OFTEN you typically utilise or consult the following sources of evidence.**

	Never	Rarely	Sometimes	Often	All

					of the Time
Expert opinion (e.g. clinicians)	•	•	•	•	•
ACT Health statistical data	•	•	•	•	•
External statistical data (e.g. ABS, OECD)	•	•	•	•	•
Existing academic research (e.g. journal articles)	•	•	•	•	•
Publications from trusted organisations (e.g. WHO, OECD, NHMRC)	•	•	•	•	•
Guidelines (clinical or otherwise)	•	•	•	•	•
Other staff within ACT Health	•	•	•	•	•
Similar policy experiences from other jurisdictions	•	•	•	•	•
Academics	•	•	•	•	•
Consultant organisations (e.g. Access Economics, Ernst & Young)	•	•	•	•	•
Consumer views	•	•	•	•	•

| Other - Please describe | • | • | • | • | • |

9. **When working on a policy development task: Please indicate how easy/difficult you typically find it to UNDERSTAND evidence from the following sources**.

	Very Difficult	Difficult	Don't use	Easy	Very Easy
Expert opinion (e.g. clinicians)	•	•	•	•	•
ACT Health statistical data	•	•	•	•	•
External statistical data (e.g. ABS, OECD)	•	•	•	•	•
Existing academic research (e.g. journal articles)	•	•	•	•	•
Publications from trusted organisations (e.g. WHO, OECD, NHMRC)	•	•	•	•	•
Guidelines (clinical or otherwise)	•	•	•	•	•
Other staff within ACT Health	•	•	•	•	•
Similar policy experiences from other jurisdictions	•	•	•	•	•

Academics	•	•	•	•	•
Consultant organisations (e.g. Access Economics, Ernst & Young)	•	•	•	•	•
Consumer views	•	•	•	•	•
Other - Please describe	•	•	•	•	•

10. **Which age group do you belong to?**

- 24 years and under

- 25-34

- 35-44

- 45-54

- 55-64

- 65 years and over

11. **What is your sex?**

- Male

- Female

- Other

12. **What level are you within your organisation? Choose the closest fit or describe**

- Project or policy officer with no management responsibilities (APS 4 -6 or equivalent)

- Middle-management or project/policy officer with some management responsibilities (EL1 or

    equivalent)

- Policy manager (EL2 or equivalent)

- Senior management (SES 1-2 or equivalent)

- Executive management or CEO

- Other - please describe _____

13. **What is your educational background and what areas did you specialise in? Please**

   choose all that apply

	Qualification	Area of specialisation
	Select all that apply	e.g. Public Health, Law, Political Science
Diploma	•	
Bachelor's Degree	•	
Bachelor's Degree (Honours)	•	
Graduate Certificate	•	
Graduate Diploma	•	
Master's Degree	•	
PhD	•	

Other - please describe	•	

14. **What would you say is your current area of expertise? E.g. Drugs and Alcohol, Mental Health, Ageing**

15. **How long (in years) have you been working in policy?**

- Less than 5 years (1)

- 5-10 years (2)

- 11-20 years (3)

- More than 20 years (4)

16. **Over the last 12 months, approximately what percentage of your work responsibilities has related to policy development (as opposed to administration or management responsibilities)?**

_____ Percentage of work responsibilities related to policy development (1)

17. **When you are working on a policy development task, what percentage of your time (rather than members of your team) do you typically spend identifying and evaluating the relevant evidence?**

_____ Time spent identifying and evaluating evidence (1)

Thank you for taking the time to complete this survey.