

# Confidence and Attitudes of General Practitioners

# towards Dementia

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### Declaration of originality

This thesis contains no material which has been accepted for a degree or diploma by the University or any other institution, except by way of background information and duly acknowledged in the thesis, and to the best of my knowledge and belief no material previously published or written by another person except where due acknowledgement is made in the text of the thesis, nor does the thesis contain any material that infringes copyright.

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#### **Statement of Ethical Conduct**

The research associated with this thesis abides by the international and Australian codes on human and animal experimentation, the guidelines by the Australian Government's Office of the Gene Technology Regulator and the rulings of the Safety, Ethics and Institutional Biosafety Committees of the University. Ethics Approval number: H0012046

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## **Publication 1:**

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# Abbreviations

Abbreviation	Definition
AMOS	Analysis of a Moment Structures
CBME	Competency based medical education
CCA	Confidence in clinical ability
CFA	Confirmatory factor analysis
CFI	Comparative Fit Index
DKAS	Dementia Knowledge Assessment Scale
DSM	Diagnostic and Statistical Manual
EFA	Exploratory Factor Analysis
GP	General Practitioner
GPACS-D	General Practitioner Attitude and Confidence Scale-Dementia
GPR	General Practitioner Registrar
GPS	General Practitioner Supervisor
КМО	Kaiser-Meyer-Olkin
NCD	Neurocognitive disorder
PCA	Principal component analysis
PCLOSE	p of Close Fit
RACGP	Royal Australian College of General Practitioners
RMSEA	Root Mean Square Error of Approximation
SD	Standard Deviation
SE	Standard Error
SPSS	Statistical Package for the Social Sciences
TLI	Tucker-Lewis Index
WHO	World Health Organisation

# Abstract

Like most Western countries Australia faces a radical increase in the prevalence of dementia. Currently dementia is the second leading cause of death in Australia and the leading cause of death among women, with approximately 376,000 cases in 2016 projected to increase to 1,100,890 by 2056[1]. The cost of supporting people with dementia was estimated to be \$9.1 billion in 2017, and projected to increase 81% to \$25.8 billion by 2036, and \$36.8 billion by 2056. As such dementia represents a significant public health issue facing Australian society in the 21<sup>st</sup> century.

It is widely acknowledged that facilitating the timely diagnosis of dementia offers the opportunity for patients and their families to plan for the future, access treatments and support services, reduce family member stress, enable caregivers (who, in most cases, are family members) to adapt to the caregiver role, provide effective support and delay admission to residential aged care. Importantly, early diagnosis enables people with dementia to actively participate in decision making about the future whilst they are able.

General practitioners (GPs) play a key role in supporting people with dementia and their families across the dementia trajectory. Importantly they have a primary role in facilitating a dementia diagnosis, a point which many GPs acknowledge. Indeed, in the majority of cases involving dementia the GP is the first health professional to be consulted. Yet while the literature suggests GPs have positive attitudes toward caring for people with dementia, many people with dementia symptoms remain undiagnosed. Of concern, evidence suggests that a third of GPs never disclose a dementia diagnosis or do not routinely disclose a diagnosis to a patient. Moreover, recent research highlights that just over half of adults with probable dementia have either not been diagnosed or were unaware of their diagnosis.

There are several potential reasons why dementia diagnosis rates remain low, or why a diagnosis might be delayed. Patient barriers include stigma, reluctance to know a diagnosis of dementia, refusal to be tested or treated, concealment of symptoms, together with minimisation of, or ignoring early signs and symptoms.

From a GP perspective, barriers to diagnosis often revolve around the difficulties associated with diagnosing dementia given the often-complex presentations,

especially in its early stages. Evidence also highlights problems with GPs' knowledge and skill deficits, while low rates of diagnosis or delayed diagnosis have also been associated with a GP's attitudes surrounding the benefits of making a diagnosis, the efficacy of medical treatments and/or confidence in their clinical abilities to not only diagnose and communicate a diagnosis, but also treat and or manage dementia related symptoms.

While training has been shown to increase the knowledge of participants, research has also indicated that knowledge is only one part of the equation in the translation of knowledge into clinical practice, and that attitudes and perceptions of self-efficacy play a key role in relation to how a GP might approach management of dementia. A survey that is both valid and can reliably measure these constructs provides insights into how educational interventions impact on attitudes and confidence, as well as providing a basis from which to develop future interventions that specifically target any deficiencies in either.

### **Research aims**

While several studies have utilised questionnaires to measure both the attitudes and confidence of GPs as they relate to dementia, most of these have been cross sectional or *ad hoc* in nature and/or are unsuitable for use within a pre-test posttest scenario. Further, very few have undertaken a comprehensive assessment of their validity and or reliability. Therefore, the main aim of this research has been to develop a reliable and valid tool to measure the attitudes and confidence of GPs both at baseline (or as a 'one off' measure) and after an educational intervention.

Consequently, the aims of this research were to:

1. develop and test a preliminary tool to measure the attitudes and confidence of GPs towards the diagnosis, treatment, and management of dementia;

2. refine and validate the tool including with confirmatory analysis. Further, undertake a comparative analysis of GP participants to test the efficacy of the tool in relation to group differences and in measuring the confidence and attitudes of GPs as they relate to the diagnosis, treatment, and management of dementia;

3. employ the validated survey to measure the impact of dementia education workshops on GP Registrars and GP Supervisors.

### Method

The sample frame comprised General Practitioner Registrars (GPRs) and General Practitioner Supervisors (GPS) undertaking dementia education workshops in five Australian states, while purposive sampling was employed to recruit participants. Phase one involved the collation of potential survey items to be included in the tool via a literature review. Potential items were evaluated for content and face validity via the use of focus groups and an expert panel. Reliability and sensitivity to change were established through an analysis of pilot data and the preliminary model developed using principal component analysis (PCA). Stage two involved the use of confirmatory factor analysis (CFA) to refine the tool and evaluate construct and discriminant validity. Stage three involved testing the tool in a cohort of participants in dementia education workshops conducted throughout Australia.

### Results

Initial results indicated that the preliminary survey exhibited sound psychometric properties with items exhibiting reliability and sensitivity to change. Subsequent refinement CFA resulted in a 3 factor, 15 item tool exhibiting good fit and sensitivity to group differences where expected. Use of the tool in dementia education workshops indicated significant increases in confidence and attitudes for participants in both GP Supervisor and GP Registrar workshops, with GPRs exhibiting the strongest effect as a result of the educational intervention.

The preliminary study indicated the General Practitioner Attitudes and Confidence Scale - Dementia (GPACS-D) comprised four potential subscales describing (a) confidence in clinical abilities; (b) support for early diagnosis, quality of life and care; (c) engagement; and (d) communication about dementia progression. Results were interpreted with reference to theories of behaviour that relate to attitudes, perceptions of self-efficacy and an intention to act or actual behaviour. Reliability and sensitivity to change were acceptable. Internal reliability scores indicated moderate to good internal consistency. In its preliminary form the tool was restricted to item level analysis because the preliminary scales had not been confirmed via confirmatory factor analysis to establish both construct and discriminant validity.

Subsequent refinement and validation via CFA reduced the original 20 item GPACS -D to 15 items comprising three subscales. These include *Attitude to care*,

*Confidence in clinical abilities* and *Engagement*. Post hoc analyses eliminated *Attitude towards communication*. The grouping of each item within each factor is reflective of reported barriers to early or timely diagnosis. Construct and discriminant validity were evidenced by goodness of fit statistics and inter item correlations.

Results from the administration of the GPACS-D provided insights into GPR and GP Supervisor attitudes and confidence in relation to each of the subscales. Intra group analysis revealed significant change because of the intervention, while inter group analysis identified significant differences between GPR and Supervisor groups in relation to each of the subscales. GP Supervisors recorded a higher score for each subscale at baseline and after the intervention for *Confidence in clinical abilities* and *Engagement*, while GPRs recorded a significantly higher score for *attitude to care* post workshop. The GPR group also recorded the greatest effect for *Confidence in clinical abilities* and *Engagement* as a result of the intervention.

### Discussion

GP attitudes towards dementia and perceived confidence in clinical abilities have been identified as barriers to the timely diagnosis of dementia. While traditionally, knowledge and skills have been the focus of educational interventions, the impact of attitude and confidence have increasingly been recognised as crucial in GP response to the diagnosis and treatment/management of dementia.

In order to assess the impact of any educational intervention, tools that accurately measure not only change in knowledge/skills but also attitudes are fundamental, because the manner in which dementia is approached and managed has been identified as a gap in preparation for practice. Attitude is a key determinant in the assessment of dementia and a tool that accurately measures attitudes and confidence is important in the development and assessment of any educational intervention aimed at changing or affecting behaviour.

The General Practitioners Attitude and Confidence Scale - Dementia (GPACS-D) was designed to measure GP confidence and attitudes towards the management of dementia as well as gauging the impact of dementia educational interventions and any change in attitudes and confidence as a result of an educational intervention. Further the use of subscales provides a more in-depth understanding of the attributes of attitudes and confidence as they relate to dementia in general practice. Through the targeting of specific components of attitude and confidence

in educational interventions, positive change in clinical practice might be achieved to enhance the quality of care for people with dementia.

## Conclusion

Current tools used to measure attitudes and or confidence have been limited in their scope. Results from this study indicate that the GPACS-D is a reliable and valid tool that is useful for measuring the confidence and attitudes of participating GPs and effect of educational interventions. Results from the application of the GPACS-D in a workshop context indicate that the attitudes and confidence of both GP Supervisors and GP Registrars can be improved which has implications for dementia education within general practice.

# Chapter 1 - Introduction

Dementia is a major health issue. It is the second major cause of death nationally and the major cause of death among women [1]. It is also pervasive in its impact at an economic, social, and individual level. Dementia does not just affect the individual with the syndrome but also those around them. Family members (who also tend to be the carer in many cases) [2], and others in close proximity, are at times negatively affected both physically and mentally.

Statistics suggest that a large number of individuals who have symptoms of dementia go undiagnosed or do not receive an early or timely diagnosis, and while there are arguments both for [3-6], and against early diagnosis [4, 7-10], the consensus of opinion appears to be that the benefits of early or timely diagnosis outweigh any potential negative effects [11, 12]. Yet while early recognition and diagnosis have been identified as beneficial for the person with dementia and their families, diagnosis often occurs later rather than earlier [13].

By making an early diagnosis, people have the opportunity to access any recent advances in drugs to alleviate the symptoms of dementia, family, relatives and carers can access respite and support services [14, 15], but more importantly, the person with dementia can play an active role in decision making about their future whilst they are able.

### Background

General Practitioners (GPs) are often the first point of contact for patients with dementia and are pivotal in facilitating early diagnosis of dementia and may be the only person who undertakes the diagnosis [16]. While international research indicates that rates of diagnosis have improved over the last 10 years [17], recent research indicates that between a third and one half of GPs do not undertake a formal assessment when a patient presents with cognitive symptoms [5, 18-21].

The reluctance among some GPs to identify dementia and to follow up with a formal diagnosis, or refer to an appropriately qualified medical specialist may reflect their level of knowledge and attitude towards the condition or a perceived lack of confidence in their ability to diagnose dementia [22]. Inadequate detection, referral and management have been documented in Australia and internationally, leading to people with dementia and their families missing out on optimal pharmacological and psychosocial interventions [23, 24].

There are several reasons why a diagnosis of dementia may be missed or delayed including patient or caregiver, societal and GP factors. For the GP, these factors include a lack of awareness, little or no education about dementia, limited diagnostic skills, no definitive diagnostic test, negative attitudes towards diagnosis, the absence of available treatments to alleviate or curing the condition [7, 10, 24-28], or effective management strategies post diagnosis.

Improving GPs' knowledge and skills through educational interventions has been reported as a means to not only improve competence and capacity and diagnosis rates but also encourage a more active role in the management of people with dementia. However, other research suggests that low rates of dementia diagnosis are not only a result of knowledge and skills deficits that can be improved through education but also are a result of failure to change practice [29]. GPs' fundamental knowledge of dementia is adequate [30, 31], and they can recognise dementia, yet do not change their practice, suggesting that other factors in addition to knowledge are involved.

Increasingly, the attitudes of GPs towards diagnosis and treatment, and a perceived lack of confidence in clinical abilities, have been identified as barriers to diagnosis within a clinical setting and are important factors in relation to the extent to which GPs will engage a patient presenting with dementia related symptoms. Indeed, it has been reported that a physician's attitude towards dementia rather than their knowledge represents the key determinant of whether they conduct a full assessment [27, 32, 33]. And while knowledge is of importance in improving the skills base of GPs to identify and manage dementia, it is only one part of the equation in the translation of clinical knowledge into clinical practice.

The aim of dementia education is to bridge the gap between clinical knowledge and clinical practice by increasing the capacity of GPs to diagnose and treat patients who may present with dementia, and which may improve GP knowledge of the signs and symptoms of dementia, provide information on current therapies and external resources (e.g. respite services), as well as assessment guidelines and instructions on their use [7, 34].

Educational interventions have typically been promoted as a means to not only increase the knowledge base of GPs, but also to improve both diagnosis and disclosure rates [82, 132]. Less focus has been placed on the impact of dementia training or education on other important contributors to practice such as confidence and attitudes [198]. Inadequate knowledge creates uncertainty, and

this uncertainty can negatively impact on multiple aspects of the doctor-patient relationship such as communication about diagnosis and treatments. Effective education could increase the confidence of GPs to undertake discussions [202].

Effective education for GPs should equip them with more than practical skills, such as the knowledge, attitude, and confidence to apply these skills to dementia in practice. The dementia education workshops that were central to this study were developed to support both GPs and GPRs in this regard. The work presented in this thesis was part of a large project which also involved the design and delivery of the educational workshops, which measured the knowledge levels of GPs using the Dementia Knowledge Assessment Scale (DKAS). The GPACS-D was developed to complement this knowledge test to measure both attitudes towards diagnosis and care, and confidence in clinical abilities to diagnose and manage dementia [203].

Developing the GPACS-D was important because the attitudes of GPs play an important role in influencing their decision making related to diagnosis, disclosure, and management of dementia [16, 22, 28, 38, 119]. Similarly, GPs' confidence in their capacity to undertake a diagnosis and manage the behavioural symptoms of dementia has also been identified as a barrier to their initiating a diagnostic process. In this case confidence refers to an individual's perceptions of their capacity to undertake a specific task [80]. Given this, it was recognised that while increasing knowledge and skills can impact on diagnosis rates [7], confidence and attitudes towards the dementia diagnosis and care also play an important role in relation to the GPs' engagement with a diagnostic process and subsequent diagnosis rates, as well as post diagnostic care [123, 129, 204]. In order to explore these relationships, I needed to be able to measure the impact of dementia education on GP attitudes towards, and confidence in, diagnosing and managing dementia. Hence the imperative to develop the GPACS-D instrument.

Currently the effectiveness of educational interventions, in the main, is measured by a dementia knowledge test [35, 36] and, in some cases improvements in diagnosis rates [37]. Other research has reported on GPs' general attitudes and practice towards specific aspects of dementia recognition and management such as screening and disclosing a diagnosis to patients with dementia [25, 30], comparative analyses of GP attitudes to early diagnosis [38], and self-reported competence and attitudes of GPs towards patients with dementia [39]. While these studies do address GP attitudes and, to a lesser extent confidence, to date no validated questionnaire has been developed to address attitudes and confidence specifically and measure the impact of education on these parameters, and few have been administered within a pre-test post-test scenario, in a dementia education setting.

In relation to dementia education programs, no attempt to measure changes in both confidence and attitudes prior to and after an intervention have been undertaken and reports of the psychometric properties of measures are limited.

### Aims

This study has focused on developing a reliable and valid tool to measure attitudes and confidence of GPs with respect to dementia, suitable for determining any change in these parameters occurring as a consequence of education. Elements from established theories of behaviour addressing attitudes and self-efficacy and their relationship to behaviour were utilised to inform the study [40, 41]. Both concepts have been identified as being associated with intention to act or actual behaviour and were employed as the basis from which to address questions surrounding the relationship between knowledge, attitudes and self-efficacy and are a common theoretical framework used for research conducted within health care and other settings.

The proposed research is driven by the following broad questions, which are being addressed as part of a large project:

- What is the relationship between knowledge, confidence, and attitudes of GPs in the context of dementia?
- Does targeted educational intervention impact on knowledge, attitudes, and confidence?

The research presented in this thesis will focus specifically on the following aims:

- develop and test a preliminary tool to measure the attitudes and confidence of GPs towards the diagnosis, treatment, and management of dementia;
- 2. refine and validate the tool including with confirmatory analysis. Further, undertake a comparative analysis of GP participants to test the efficacy of the tool in relation to group differences and in measuring the confidence

and attitudes of GPs as it relates to the diagnosis, treatment, and management of dementia;

3. employ the validated survey to measure the impact of dementia education workshops on GP Registrars (GPR)s and GP Supervisors (GPS)s.

### Approach

To address these questions and research aims the research process was broken down into three distinct stages.

*Stage 1:* exploratory techniques were used to identify potential survey items and assess content and face validity. This included undertaking a literature review of research and survey-based studies addressing attitudes, confidence, and other barriers to diagnosis to compile a preliminary set of survey items for further development. Focus groups and an expert panel were utilised to establish face and content validity. The tool was piloted, and quantitative methods were employed to establish reliability, sensitivity to change and the assessment of the preliminary psychometric properties of the proposed tool.

*Stage 2:* survey validation was achieved through the application of confirmatory factor analysis to assess model fit and construct and discriminant validity. Quantitative methods employing both nonparametric and parametric techniques were employed to establish reliability, sensitivity to change, psychometric properties and validity of the tool including construct and discriminant validity.

*Stage 3:* the GPACS-D was then used within a workshop setting to determine if GPs and GPRs differed in their confidence and attitudes to dementia and whether changes in attitude and confidence were evident following targeted education.

## Significance

The early diagnosis of dementia provides an opportunity to access therapies and support beneficial to the patient and family [32], and provides the opportunity for timely attention to underlying or coexisting treatable conditions and the provision of information about diagnosis and prognosis. Importantly, early diagnosis provides an opportunity for the dissemination of information about how to respond to the condition as it progresses, what support services are available and how to access them [23].

Dementia does not just affect the individual with the condition but also those who care for them. Research suggests that family care givers experience impacts on physical health, mental health and increased risk of mortality [13, 42]. Therefore, timely diagnosis may prevent crises and provide an opportunity for patients and families to adjust to the condition and plan for the future [14].

While there is evidence to indicate that diagnosis can cause a number of negative reactions such as shock, anger, and depression [94], this is not the case for all of those to whom a disclosure is made. Other research indicates that early diagnosis is generally received positively by the person with dementia and that people have a preference to receive a diagnosis sooner rather than later [22, 43]. Early diagnosis may reduce anxiety associated with a lack of certainty [215] and allow patients, carers and family, time to come to terms with the condition [38]. Understanding the role attitudes play in the early diagnosis of dementia provides the opportunity to effect change in relation to how dementia is approached, diagnosed, treated, and managed.

While knowledge and skills are important in relation to improved confidence and capacity to effectively undertake a diagnosis, attitudes, it is argued, are also important in relation to how a GP approaches early or timely diagnosis and the extent to which they might engage with someone with dementia.

Results from this study provide medical educators and other health professionals with a tool that offers insights for developing tailored targeted interventions based on components of confidence and attitude contained in the GPACS-D. This tool will potentially help direct educational resources to areas of deficiency in confidence and attitudes which are likely to have the greatest impact on practice change.

## Outputs

- a method and tool to collect and measure confidence and attitudes as well as measuring the impact of educational interventions on confidence and attitudes;
- add to understanding of the relationship between knowledge, confidence, attitudes of GPs toward dementia;

- basis from which to develop curriculum that addresses any deficiencies identified via examination of the components of confidence and attitudes found in each the survey's subscales;
- potential application of the method and tool to other educational scenarios.

### **Thesis structure**

### Chapter 2: Literature review

A literature review was undertaken to explore attitudes and confidence toward dementia and develop a set of potential survey items to be included in the GPACS-D. Chapter 2 outlines the incidence of dementia, who is at risk and the cost to the community both economically and socially. Specific focus is applied to literature addressing barriers to diagnosis and studies employing questionnaires that measured the attitudes and confidence of GPs in relation to the diagnosis and care of someone with dementia. Additionally, the role of education in improving GP competence and diagnosis rates is also covered. Lastly, the tools currently used to identify and measure GP confidence and attitudes as well as current gaps are also addressed.

## Chapter 3: Method

Employing a primarily quantitative approach to the research, Chapter 3 outlines the procedures undertaken to address each of the research questions and aims and includes the rationale for the steps and methods undertaken.

### Chapter 4: Development of GPACS-D

Chapter 4 contains the final Word document of a published manuscript titled, "Development and preliminary psychometric properties of the General Practitioner Attitudes and Confidence Scale (GPACS-D) for dementia"; published in BMC Family Practice in August 2016. This paper describes the processes undertaken to deliver a preliminary survey tool to measure attitudes and confidence towards dementia in participating GPs. Key findings include that the preliminary tool exhibited reliability, sensitivity to change and preliminary valid psychometric properties.

### Chapter 5: Confirmation and validation of the GPACS-D

Chapter 5 contains the final Word document of the published manuscript titled, "General practitioner attitude and confidence scale for dementia (GPACS-D): confirmatory factor analysis and comparative subscale scores among GPs and supervisors" published in BMC Family Practice in June 2019. This paper describes the refinement and validity testing of the preliminary survey tool through confirmatory factor analysis and a comparative analysis between each professional group. Key findings include the reduction of the original 20 items to 15 items comprising three subscales that exhibited good fit and construct and discriminant validity, and fair to acceptable internal consistency.

### Chapter 6: The impact of dementia education

Chapter 6 presents the final Word document of a published manuscript titled, "Effect of a dementia education intervention on the confidence and attitudes of General Practitioners in Australia: a pre-test post-test study"; published in the British Medical Journal Open (BMJ Open) in January 2020. This paper describes and compares the confidence and attitudes of GPRs and GPs and examines the impact of attendance at a dementia education workshop within and between these groups in attendees at educational workshops conducted throughout Australia. As a supplement to the study, and because these data were collected as part of a larger project which included a knowledge measure, data are presented which examine the relationship between knowledge (as measured by the Dementia Knowledge Assessment Scale (DKAS)), Confidence in clinical abilities, Attitude to care and Engagement. Key findings include that targeted educational interventions are effective in improving Confidence in clinical abilities, and Attitudes towards dementia care and Engagement. Knowledge as measured by the DKAS indicates that knowledge impacts Confidence in clinical abilities and Attitudes towards care and Engagement.

### **Chapter 7: Discussion**

In this chapter I consider the importance of being able to measure attitudes and confidence towards dementia in GPs and how this might impact on our approach to delivering dementia education which ultimately benefits people living with dementia.

# Chapter 2 - Literature review

### Introduction

Dementia is a neurocognitive disorder (NCD) that *is not* a normal part of ageing. The term 'dementia' describes a collection of symptoms caused by disorders affecting the brain which affect cognition, behaviour and the ability to perform everyday tasks and interferes with the person's normal social or working life [44]. The Diagnostic and Statistical Manual (DSM 5) identifies two types of cognitive decline; mild neurocognitive disorder and major cognitive disorder and lists 6 cognitive domains in which there may be deficits in mild and major forms of NCD [45].

Mild NCD has been included as a category of NCD because of the increasing number of people presenting at clinical practice for assessment and treatment for cognitive decline. While mild NCD does not necessarily mean that the person will progress to major NCD, the shift to early diagnosis is a response to the long predementia stage, improvements in early diagnosis and the emphasis on the positive benefits of early or timely diagnosis[46].

Alzheimer's disease is the most common cause of dementia, accounting for approximately 50% to 75% of dementia cases worldwide [47] followed by vascular dementia (20%-30%), and dementia associated with Lewy bodies (5%). Mixed dementia occurs in approximately 20% of cases. Frontotemporal degeneration (5%-10%) and dementias associated with brain injury or alcohol abuse are less common causes [44].

### Scale of the problem of dementia

Global prevalence estimates indicate that there were 46.8 million people with dementia in 2015, with close to 50 million in 2017 [47]. This figure is expected to increase to 75 million in 2030 and 131.5 million in 2050. As the world's population ages, increasing numbers of people are living with dementia and this is projected to continue to rise, especially in low- and middle-income countries.

In 2020, 459,000 adults were estimated to be living with dementia in Australia with women accounting for over 50% of cases (56%) [44, 48]. While around 75% of those with dementia are aged 75 years and over, 27,800 Australians are living with younger onset dementia [44].

In Australia, the Australian Institute of Health and Welfare (AIHW) indicates that the Northern Territory has the highest incidence of dementia in Australia and is its poorest state or territory [1].

Projections suggest that the rate of growth will slow [44], however the absolute number of cases of people with dementia will obviously increase with future population increases and the continual ageing of the Australian population.

These figures may well underestimate the actual incidence of dementia in the community because there is no 'official' registry for recording cases and the methods used to calculate incidence vary between studies. Compounding this issue is the historically low rate of diagnosis [21], and while British research indicates that diagnosis rates have improved [17], other research estimates suggest that only half of all people with dementia have received a diagnosis [7, 18, 28]. Further, individual, public, and professional attitudes towards dementia can also impact on diagnosis rates and as a result the number of cases of dementia formally diagnosed and counted.

Alzheimer's Australia, [49] employing ABS statistics, reports that there is no agreement on how best to estimate costs associated with dementia and that study methods and techniques to establish costs differ amongst studies. Dementia presents an enormous economic cost to Australia. In addition to the direct cost of care for people living with dementia (including general practitioner consultation, specialist visits, hospitalisation estimated to be 36.8 billion in 2056), indirect costs such as loss of productivity, not only of those living with dementia but also of those that provide care must be taken into account. At present, without an intervention which reduces the rate of progression, or the incidence of dementia, it is estimated that dementia will cost in excess of \$26 billion by 2036. As such dementia represents a significant public health issue facing Australian society in the 21<sup>st</sup> century.

## Who is at risk of dementia?

While dementia is strongly correlated with age, it can affect younger people. According to Breitner [50] the proportion of dementia cases rises proportionally with age, from 10% at 80 years of age to around 50% at age 95 or older with the incidence doubling with every five years of age increase.

Other age-related health issues are associated with dementia; therefore, people tend to present at general practice with co-occurring conditions. Other conditions

such as diabetes, hypertension and high cholesterol, increase the risk of Alzheimer's disease and vascular dementia [5]. Other modifiable risks include lack of physical activity, obesity, low social engagement, alcohol consumption, smoking, which have been potentially linked to a lack of resilience and repair contributing to these problems.

#### Does early or timely diagnosis matter?

Obtaining a diagnosis of dementia for a relative can be a drawn out and anxious time for family members, who, for the most part, are providing care for someone with symptoms of dementia [2]. Wackerbath et al [51] reported that some patients are delaying assessment for nearly two years after symptoms first emerge. In Australia it has been estimated that 3 years elapse between initial symptoms being evident and a formal diagnosis being sought [1]. Of note is the time it also takes between consulting a GP and obtaining a formal diagnosis [92]. This delay can have considerable consequences in relation to undertaking a timely diagnosis and effective treatment and management. Given the length of time it takes to make a diagnosis, and that current screening tools do not definitively via current screening tools. Indeed, the length of time it takes to get a formal diagnosis can have negative effects such as anxiety and depression not only for the person with dementia, but those around them [65, 75].

A timely diagnosis has been defined as a diagnosis at a time when the person with dementia and their carers are ready for it, and which benefits the person by providing person-centred care and responding to the individual needs and preferences of the person with dementia [5, 92]. The importance of appropriate timing of the diagnosis is indicated by the varying reactions to, and readiness for diagnosis between people diagnosed.

A 'timely diagnosis' does not necessarily mean 'early diagnosis' and there has been a shift away from discussing the merits of early diagnosis to instead discussing timely diagnosis [14]. Determining timely diagnosis, however, is not clear cut and is dependent on the views of the patient, family/carer, and practitioner. This approach can prove problematic if each of these groups have disparate views about whether a formal diagnosis should be undertaken.

There is considerable discussion around the benefits or otherwise, of an early or timely diagnosis. Proponents argue that benefits include improved access to treatments, the provision of support and services for people living with dementia and their families, reduced family member stress, and delayed admission to residential aged care [14]. Although some people do not wish to know the diagnosis (and have the right not to know), people with dementia and their families find diagnostic uncertainty anxiety provoking and are often relieved by a diagnosis [19]. One study, utilising psychometric tests measuring depression and anxiety, reported that anxiety diminishes post diagnosis [94]. Werner [19] indicates that in the last decade studies consistently indicate that both the person with dementia and their carers are willing and prepared to receive and deal with a diagnosis of dementia. In a cross-sectional study undertaken by Watson and coworkers [95] a large proportion of respondents indicated that disclosure should be as soon as possible, with a high positive correlation between an individual's wish for timely diagnosis and their view about the disclosure of diagnosis of others. That is, if an individual preferred early notification of a diagnosis of dementia, they were likely to wish the same for a spouse or partner. Other research has confirmed that generally, people with dementia are in favour of receiving a diagnosis when it is known [6]. However, differences do exist.

Opponents of early diagnosis argue that because there is no cure and limited treatments available, if any, there is little benefit in making an early diagnosis [9]. The benefits of psychosocial interventions (counselling, education and support) have also been questioned with Waldorf et al [8] utilising a randomised control study and employing several psychometric tests, reporting no benefit in alleviating depression or improving quality of life among the study group [8]. Similarly, Brayne and colleagues [9] posit that the benefits of early diagnosis are often assumed [9, 96], and while some studies suggest that people would prefer to know 'early', negative outcomes in the form of anxiety, depression, and suicidal ideation do occur and may be exacerbated by the time it takes to obtain a definitive diagnosis [3].

Studies examining the link between a diagnosis of dementia and suicide have found that the suicide rate was small, and many have failed to find an association between a dementia diagnosis and suicide [97]. However, in a study of the risk of suicide and dementia, Seyfried et al [98] reported that of 136 individuals who committed suicide and who had a diagnosis of dementia, 75% occurred among those with a recent diagnosis [98]. Similarly, Draper et al [3] in a selective literature review of suicide risk in patients with dementia, note that while the risk is small (and generally associated with comorbid depression), GPs need to be aware that the risk exists. Adverse psychological reactions to a diagnosis, it has been suggested, are temporary, however any such reactions need to be addressed by education and support throughout the diagnostic phase of the consultation [5].

### **Barriers to diagnosis**

Research has indicated that a large proportion of GPs do not undertake or disclose a diagnosis of dementia with rates ranging from around one quarter to one half not disclosing the diagnosis to the patient and/or family [2, 18, 19, 28]. Many people with dementia receive a diagnosis when it is too late for them to make decisions about their own and their family's future or benefit from interventions [5]. However, GPs are not the sole source of missed or delayed diagnosis; several other factors are at play that may impact on delayed or missed diagnosis.

Patient or carer factors and external factors such as demographics and stigma potentially impact diagnosis delay or missed diagnosis. Wackerbarth et al [51] reporting the results of a survey of family caregivers indicated that respondents who were younger, visited a rural assessment clinic, and had less education were more likely to have a delayed or missed diagnosis and experience more barriers to diagnosis than their older, educated and urban counterparts. Fischer et al [52] identified increased age, low education, high medical comorbidity and low annual income as being associated with a diagnosis of dementia in an inner-city setting indicating that age, poverty and poor educational outcomes are barriers to diagnosis. Additionally, people from some ethnic groups delayed diagnosis until the later stages of the disease and were less likely to recognise symptoms, as well as suffer greater stigma [53]. Similarly, individuals who live alone have been reported to be at greater likelihood of a delayed or missed diagnosis [21]. These individuals are less likely to have support persons or mechanisms in place and may have very limited, if any contact with a GP. Therefore, rurality, age, income, education, and ethnicity all impact the likelihood of obtaining or seeking a diagnosis.

For many, the stigma associated with dementia influences the likelihood that a diagnosis will be sought or made, and this remains a major challenge.

### **Patient and Carer Factors**

#### Stigma

Stigma has been identified as a major barrier to an early or timely diagnosis of dementia and contributes to a delay between recognition of the signs and symptoms and a decision by the person or family member to seek professional help. From a GP perspective, the potential negative impact of stigma in relation to social isolation, reduced autonomy, and loss of status, as well as the patient's emotional wellbeing, impact on decisions surrounding when to diagnose and how to disclose a diagnosis and to whom.

In Erving Goffman's [54] theory of stigma, a stigma is described as a mark or stain, an attribute, characteristic, trait or behaviour which is labelled as socially undesirable, leading to discrimination, social isolation and disenfranchisement. The stigma associated with dementia is associated with attributes (psychological and physical degeneration) that set it apart from what is considered or constructed as normal. The attributes of dementia encompass both psychosocial and physical characteristics, with estimates indicating that behavioural changes occur in 80 to 90% of cases, while personality or psychological impacts are evident in 70% of cases[55]. Psychological symptoms include depression, anxiety, psychosis, agitation, aggression, disinhibition, paranoia, forgetfulness, confusion, delusions, and hallucinations. Physical behaviours associated with dementia include irritability, functional loss, such as mobility and continence, sleeplessness, verbal, or physical aggression and wandering. These attributes or behaviours progress from mild to more severe with the stages of dementia [11, 55], thereby increasing the likelihood of stereotypes being applied and discrimination occurring [10]. It is the expression of these attributes that elicits a response from others at an emotional, cognitive and behavioural level [56].

The stigma of dementia not only affects the person with dementia but also those in close proximity, such as a spouse or family member(s), and has implications in relation to seeking help, delaying a diagnosis, refusing a diagnosis or social isolation caused by avoidance or withdrawal from social interaction [57, 58].

Three types of stigma can be described: self-stigma which occurs when the person internalises discrimination leading to negative outcomes such as a reluctance to seek help, refusal to be tested or treated, social isolation and withdrawal from social life; public stigma which manifests itself as discrimination aimed against the person with the stigma including exclusion from social life and decision making; and courtesy stigma which affects those in close proximity to the person who is the subject of stigma. The effects of courtesy stigma are similar to the impact of public stigma such as social isolation and exclusion. Each of these aspects of stigma manifest in dementia.

Responses to the stigma of dementia are dependent, in part, by issues of exposure (how evident the attributes of dementia are), the source, or cause of the stigma, and the extent to which the individual is perceived as being responsible (the source of) for the stigma [59]. Where the cause of the stigma is physical or genetic and the individual is perceived as not causing the stigma through their own actions, pity, sympathy, compassion and a desire to help ensue [59, 60].

Werner [60] indicates that people with dementia elicit more positive than negative emotions from others and do not suffer high levels of social rejection, and that being associated with someone with dementia carried less stigma than being associated with someone with schizophrenia or another mental illness. As such attitudes towards the individual are less likely to be negative, yet negative attitudes towards the condition and diagnosis may remain. Ashworth reports that while respondents reported low levels of agreement with the Stigma Impact Scale, nonetheless it was reported that the person with dementia and their carer suffer stigma, but that the stigma was expressed as feelings of shame and social rejection resulting from the impact of the disease symptoms [61].

However, while the response to an older person with dementia may be more empathetic rather than negative, GPs report the potential negative impact of the stigma associated with dementia as being a major concern for them with regard to diagnosis and disclosure [11, 62].

While the fear of dementia may, in part, be a response to the impact of the stigma of dementia, the fear of a dementia diagnosis also revolves around the dread of the condition, its terminal nature, the significant physical and cognitive decline, and a lack of effective treatments [13, 63]. For the person with dementia the fear of their inevitable decline, both physically and psychologically, and attendant feelings of shame and humiliation can lead to attempts to conceal dementia from everyone including the GP [7]. However, these fears are not limited to the person with dementia but also those close to them such as carers and family members [64].

Exposure to dementia provokes angst and notions of mortality, while a diagnosis of dementia in the person may result in a fear of confirming one's own risk of

dementia, especially if they are a family member [51, 65]. For those in close proximity to someone with dementia the experience of witnessing the psychological and physical deterioration of the individual can be both confronting and challenging. While sympathy, compassion and pity may be common responses to someone with dementia, this does not reduce the negative consequences that may accrue as a result of a diagnosis of dementia, which not only impacts the person with dementia but also (to a lesser extent), carers and family members [11, 19].

Family members have reported difficulty in accepting their family member's decline and worry how the diagnosis will impact their life [67]. Research for the World Alzheimer's Report (2019) suggests that just over a third of carers have hidden the diagnosis of a person with dementia [68]. Delaying or refusing a diagnosis may result from a fear of the diagnosis, or of the negative consequences that result from a diagnosis. In a qualitative study involving semi structured interviews with GPs in the UK, the authors report that stigma is still a barrier to seeking a diagnosis, with some GPs indicating that patients fear dementia because of the stigma attached to a diagnosis and this, along with a lack of effective pharmacological treatments, dissuades people from undertaking a diagnosis [26].

Patients who deny or who present reluctantly are especially prone to a delayed or missed diagnosis [16]. While Werner[11] report that people with dementia and their carers/family do not experience the negative effects of stigma compared to other conditions, other studies have shown that resistance to a diagnosis results from fears associated with social exclusion, isolation, loss of status and independence [12, 69], and that in a number of cases both the person with dementia and their families will attempt to conceal the condition from neighbours, friends and their GP, or avoid a diagnosis to protect the patient's autonomy [19, 70]. These avoidance tactics present an additional layer of complexity for the GP in their ability to undertake and disclose a diagnosis of dementia.

A fear of diagnosis may also lead carers (who are for the most part family) [44] to compensate and cover up for lapses of memory experienced by the person with dementia [71]. Both family and carers may be hesitant about reporting memory problems to GPs through fear of a loss of identity, shame or the impact of stigma and social isolation (for both the person with dementia and their family) or institutionalisation that may result [26, 72].

A desire to maintain identity and social contacts also encourages the development of strategies to minimise or normalise the condition [53], while the desire to maintain status and protect the individual (from both the individual and their carer/family perspective) may lead people (both the person with dementia and their carers/family) to avoid or delay a diagnosis until it is absolutely necessary, or when the psychological and behavioural symptoms of dementia eventually force their hand [13, 51, 73].

A small number of people with dementia report a preference not to know their dementia status [6]. Emotional difficulties can arise as a result of acknowledging and confirming a problem exists and family members also have to adjust to both prospective loss and confirmation that their lives have changed [32, 216]. Results from a qualitative study of 50 patients and 50 carers regarding a dementia diagnosis, indicated that respondents who did not want a diagnosis reported they simply "did not want to know", and that disclosure of a diagnosis would "upset them", while reasons for not wanting to undertake a test for dementia also included the perception that there is no cure for dementia. In this context treatment options are perceived as limited in alleviating symptoms or curing the condition [6]. It should be noted that the proportion of patients who did not want a diagnosis or testing is typically small, with the majority both preferring to know and wanting a diagnostic test, citing a right to know and the ability to plan for the future as reasons [6]. Additional research has also indicated that patients often present with multiple co-morbidities and view cognitive decline as a secondary issue to other (physical) ailments [32, 74] and therefore do not consider it a priority, unless the primary goal of a visit to the GP was to discuss memory problems [74].

### Knowledge and attitudes

A lack of knowledge or awareness of dementia among people with dementia and carers is commonly reported as an obstacle to diagnosis [12], with delays in diagnosis a result of the misunderstanding of cognitive decline and older age. In this scenario the carer or the person with dementia may perceive cognitive decline or changes in cognition as a regular part of ageing and therefore not consider it to be pathological or may fail to recognise symptoms or misdiagnose them as something else [7]. The World Alzheimer's Report (2019) indicates that around two thirds of respondents thought that dementia was a normal part of ageing and that over half were of the view that lifestyle factors played a part in developing dementia [47].
In a meta-analysis of qualitative studies exploring experiences of dementia diagnosis, the perception that symptoms of dementia are a normal part of ageing is referred to as the normalisation of symptoms [53] and represents a lack of awareness about the signs and symptoms of dementia. In a German study comprising 1,002 telephone interviews, it was reported that a willingness to undertake a diagnosis was based on the perceived effectiveness of preventative behaviours (e.g. mental stimulation) and the erroneous belief that effective treatments were available. The authors found that this view was more prevalent among poorly educated males and posited that this perspective was a result of their lack of exposure to people with dementia and that low education was in fact a proxy for lower knowledge about dementia [77].

These results suggest that both patients and caregivers may lack an understanding of the difference between memory processes in ageing and dementia. The symptoms of dementia may be confused with normal signs of ageing and may in fact mask other motives for delaying a diagnosis.

# **GP Factors**

## GP Responses to dementia

Like those living with dementia and carers, GPs have beliefs about dementia that impact their attitudes towards it and consequently the way they might approach someone with dementia or a diagnosis [29, 38]. What is common to all groups is that attitudes appear to revolve around the dread of the condition itself in relation to its terminal nature and attendant loss of cognitive function, the impact of stigma relative to loss of status and exclusion, beliefs surrounding the utility or benefits of diagnosis, the effectiveness of treatments and the availability of post diagnostic treatment and care [7]. GPs describe feelings of fear towards dementia and the interaction as burdensome [22], and may respond to a diagnosis with disbelief, denial, apprehension and fear, especially if they have known the patient for a long time [29, 66].

Gove et al [10] reported that GPs preferred terms other than dementia, suggesting that patients were more comfortable talking about 'short term memory problems', rather than 'Alzheimer's'. The same study found that GPs emphasised the importance of being sensitive to patient fears of dementia and caution when broaching the topic of dementia because of the potential impact of the label (emotionally and in terms of discrimination), and the lack of effective treatments.

For GPs, the stigma of dementia can act as a barrier to a timely diagnosis. This does not mean that the GPs themselves delay a diagnosis of dementia as a personal response to the stigma of dementia but that patients and or families delay seeking a diagnosis in light of the potential negative emotional and discriminatory consequences of being labelled [65, 73, 75]. These attitudinal perspectives or beliefs can result in denial and a refusal to be tested after initial screening or for further interventions post diagnosis [76]. GPs may also postpone a diagnosis as they attempt to reconcile patient fears and the impact of the diagnosis against the benefits that may accrue from disclosing the diagnosis in a timely and appropriate manner [10].

Managing a patient's denial and or refusal to cooperate is particularly difficult for GPs to overcome; if a patient does not give consent, then the GPs cannot undertake a formal diagnosis or disclose a diagnosis. Moreover, Bradford et al [7] reports research indicating that in some cases both the patient and the GP may avoid discussions of cognitive function, based on fear or a denial of any problems. It is an area where GPs report the need to be sensitive to patient fears and balance the benefits of disclosure against the wishes and needs and fears of the patient and the impact of disclosure.

The preceding suggests that patient, and to a certain extent, clinician responses to dementia emanate from two primary sources. One is the stigma associated with the condition and the consequences that flow from it including a loss of status, autonomy, social isolation and the threat of institutionalisation [64]. The other is the dread of the condition itself, its terminal nature, the physical and psychological degeneration that ensues, and the lack of effective treatments available. This dread of the condition impacts not only the person with dementia but also carers, family members and health care professionals. The terminal nature of the condition, lack of effective treatments and fear of the consequences of a dementia diagnosis may contribute towards negative attitudes towards diagnosis, disclosure and/or treatment.

For the GP, patient and carer, attitudes towards diagnosis and disclosure add another layer of complexity in making a diagnosis. Not only is dementia difficult to diagnose (especially in its early stages), given its various and insidious manifestations, but the GP also must navigate any negative attitudes people may hold towards diagnosis and is an area where they must balance the benefits of early or timely diagnosis with the expressed wishes and needs of the person with dementia and their carers/family.

## GP perspectives on early diagnosis

Studies indicate that approximately one half of GPs conduct a cognitive assessment of patients with suspected cognitive impairment, while other studies found that approximately one third of GPs fail to disclose the diagnosis [18, 25, 28]. Thus, a significant proportion of GPs are either not in favour of diagnosis or do not routinely carry them out, with a number of studies reflecting this finding [25, 99, 100].

Research indicates that GP attitudes towards the diagnosis of dementia revolve around perceptions of the efficacy of treatments and any benefits that may accrue from a diagnosis, the impact of the diagnosis on the patient and knowledge of local dementia support services [38]. Similarly, Philips et al [62] suggest that in providing a diagnosis the GP had to have confidence that the diagnosis was correct, that he/she was acting in the best interests of the patient and dealing with any negative implications of the diagnosis [62].

# GP attitudes toward dementia

Pessimism surrounding dementia prognosis and an inability to offer curative treatment [105] may lead to an attitude of 'therapeutic nihilism' (the belief that there is no treatment or cure for dementia) among GPs [13, 25]. Those GPs who hold this perception see limited value or advantage to early diagnosis which reflects a biomedical definition of treatment and an ethos centred around curing people, while simultaneously ignoring therapeutic interventions that may benefit people with dementia and their carers [7, 106, 107]. Therapeutic nihilism [13, 25], fatalism [108, 109], scepticism [109], a negative attitude towards communicating a diagnosis, and the lack of perceived benefits of doing so [27, 110] have been reported as impediments to early diagnosis and patient/carer engagement. However, recent research has suggested that GP attitudes were not characterised by therapeutic nihilism and that negative attitudes towards diagnosis were more related to a lower likelihood of providing post diagnostic care such as counselling or further assessment [111].

## GP confidence

An individual's behaviour is influenced by confidence in their ability to perform a particular set of actions or procedures. Bandura refers to this as *self-efficacy* [40], while Ajzen describes it as *perceived behavioural control*: a person's perceived capacity to undertake a behaviour or action [101]. Both terms are concerned with

an individual's perceived ability to perform a particular behaviour and the impact of this perception on their intentions to act or actual practice [101].

While improved knowledge will not necessarily result in behaviour change, an intention to act or actual behaviour, attitude alone is also insufficient. While GPs may have a positive attitude towards diagnosis, a lack of confidence in clinical abilities for example, may negate a positive attitude towards diagnosis and care. Research indicates that GPs who are confident in their clinical abilities also have a positive attitude towards timely diagnosis and management of people with dementia [112]. Thus, an individual not only requires a positive attitude but also the confidence to undertake an action or behaviour.

Confidence in one's ability to diagnose, treat, or manage dementia may be correlated with the quality of care delivered [85]. The above theoretical framework is relevant to this study because GPs have reported a lack of confidence in their diagnostic and behavioural management skills [25], while other research has indicated that GPs feel they have very little to offer patients presenting with dementia [113].

Behavioural theory suggests a relationship between perceptions of self-efficacy, the amount of effort expended on an activity or behaviour, and avoidance of those behaviours or activities that people feel are beyond their capacity [102]. Therefore, perceptions of professional inadequacy may lead to frustration and avoidance of the condition [114, 115]. A GP's hesitancy to diagnose dementia may not be explicit. Rather it may manifest in a reluctance to formalise a diagnosis or preferentially treat co-occurring conditions for which treatment options are available [16, 112], referring on because of limited treatment options [116], questioning the (traditional) role of the GP in treating dementia [117], or having insufficient resources [18].

Physicians with a negative attitude towards caring for a patient with dementia have reported a lack of belief in their ability to improve the patients' quality of life, while the opposite was reported by those with a positive attitude [39]. Such findings provide support for the conceptualisation of attitudes and confidence as co-related influences on how a GP might engage with a person with dementia [83]. It has been reported that a significant proportion of GPs felt that that they had very little to offer patients [113], and has led to a 'reluctance' on the part of GPs to diagnose dementia at an early stage [13, 108], or a belief that an early diagnosis does not benefit the patient [118]. Boise et al [32] also found that GPs could see

little benefit in undertaking an early diagnosis given the lack of effective treatments to alleviate symptoms or cure the condition [32]. Despite perceptions surrounding the benefits of diagnosis and the efficacy of present treatments it has been shown that while GPs have a positive attitude towards caring for someone with dementia they report a perceived lack of confidence in diagnostic and management skills and that despite any positive attitudes to care, a lack of confidence in ability may negate any positive attitudes and lead to an avoidance of, or delays in diagnosis [25, 27].

Given the current and projected incidence of dementia and the perceived benefits of early or timely diagnosis it is imperative that health care professionals possess the requisite knowledge, skills, confidence, and attitudes to efficiently diagnose and effectively support people with dementia as they progress through the dementia trajectory. This includes attitudes that encourage active engagement between the GP and patient/carers and the perception that early or timely diagnosis is a prerequisite to effective treatment and management of the syndrome for both the person with dementia, their carers and family.

# GP fears of misdiagnosis

Diagnosing dementia is a difficult task for GPs, especially in its early stages and requires several assessments which may be made more difficult by the presence of co-occurring conditions [22, 84], while low rates of early diagnosis have been reported as being the result of knowledge and skills deficits [23].

The uncertainty of the diagnosis, especially in its early stages, with attendant concerns of creating unnecessary anxiety and fear for the patient if the diagnosis is questionable, makes disclosing a diagnosis of dementia a very difficult task for GPs [35, 43]. Combined with time constraints faced in general practice [85], a GP may feel they have little time to read educational materials or to attend workshops [86]. GPs who experienced difficulty undertaking a diagnosis and managing dementia related symptoms were more likely to express a negative attitude towards communicating with the patients and carers [30].

In an Australian study, employing semi structured interviews with 45 GPs from urban and regional settings, GPs reported that dementia was particularly difficult to diagnose, and it was essential to get the diagnosis right. Respondents viewed dementia as a significant diagnosis and before a diagnosis is given 'you want to make sure your facts are right'(p 548) [85]. One third of GPs fail to routinely disclose a diagnosis of dementia [18, 25, 28], which may reflect both the difficulty

in diagnosing dementia, especially in its early stages, but also a lack of confidence in their diagnostic ability.

Additionally, attitudes towards GP roles have been reported as being a barrier to broaching the topic. In this case patients perceive that it is the role of the GP to instigate discussion [7], while a GP may be unlikely to engage in a discussion that they are not confident with, or when they do not have a definitive result or answer. As with other health care professionals, GPs may avoid those activities or behaviours which are perceived as exceeding their capacity [40].

Within this context GPs may delay a diagnosis through fear of misdiagnosis, especially in the early stages of the condition, with the attendant risk of fracturing the doctor-patient relationship [12]. Phillips et al. [84], noted that caution in disclosure appeared to be associated with concern about the doctor-patient relationship and suggested that a fear of misdiagnosis acted as a driver for referrals to a specialist. In line with other studies, respondents also indicated a preference for someone else to disclose the diagnosis and preferred to disclose via carers or family members rather than the person with dementia [62, 85, 87]. Of note was the observation that GPs are willing to diagnose if the result is definitive. While the sample size was small, and generalisation is limited, the authors noted that the views of GPs were uniform at each of the study sites [85].

## Communicating a diagnosis of dementia

The disclosure of a diagnosis of dementia has been identified as particularly challenging for GPs and despite improvement, gaps remain in knowledge and practice about disclosure [19]. Discussing the diagnosis and prognosis of any terminal disease is anxiety creating [88]. It has been reported that GPs may feel uncomfortable or unwilling to discuss a diagnosis because of difficulty in discussing or explaining the diagnosis with patients and or carers, or through fear of any negative reactions as described above.

There are several reasons why communicating a diagnosis can prove difficult or not occur at all. A GP may lack communication skills or face language or cultural barriers that make communication difficult if not impossible [30, 89]. Some communication problems reflect language barriers, others more general patterns of ineffective communication. GPs may have difficulty in discussing or explaining dementia specifically [7,74]. Equally, the recipient of the diagnosis and/ or the family members, may find it difficult to discuss aspects of dementia, including memory issues and often feel it is the doctor's responsibility to raise the issue [74]. The importance of GPs' communication skills is well documented [7] and training in communication and delivering bad news has been shown to increase the willingness of GPs to discuss difficult or terminal diagnoses and prognoses with patients [90]. This process, it is argued, should occur early in the relationship and be ongoing, based on patient preferences at any point in time during the consultation process [91]. By undertaking this process, an individualised approach, best suited to the patient and family may be found, with discussions taking place at a suitable and appropriate time for the patient and carers [19], reflecting an emphasis on timely rather than early diagnosis.

# **Education and training**

# Social psychological theories of the link between attitudes, confidence, and behaviour

Behavioural theories define an attitude as a person's overall judgement of persons (including oneself), objects and issues, or how favourably or unfavourably one views some object of judgement [101]. Attitudes are important because they inform our choices - our intention to act. While not causal, attitudes are posited as a potential precursor or motivator of behaviour – a predisposition [102].

These theories focus on how attitudes are formed and maintained and how they impact on behavioural intention, decisions to act, or actual clinical or health behaviours [103]. Whether an attitude is favourable or unfavourable has been reported to influence the type of response to the object of that attitude [103]. Attitude rather than knowledge is reported to be a key determinant of whether GPs undertake a full dementia assessment [32, 104], and the diagnostic and management practices of GPs towards dementia may be significantly affected by underlying beliefs and attitudes [27, 37].

Attitudes can be judgements one makes about an object or issue (for example, undertaking or disclosing a dementia diagnosis), resulting from an experience of an event (prior experiences of disclosure). From a social psychological perspective individual behaviour (how we act or behave or respond to events) can be considered to have three dimensions; cognitive, affective, and behavioural [56]. These can be used to define how we interpret experience – either directly or indirectly (cognitive), how we feel about it; the judgements we make (affective), and how we respond or act (behaviour).

Therefore, the extent to which an attitude influences behaviour is driven by prior experience, existing beliefs, disposition toward (for or against) the object of the attitude and contextual factors. Thus, attitudes towards the diagnosis or disclosure of a dementia diagnosis could be influenced by one's views about dementia (the benefits or otherwise of diagnosis) and understanding of dementia disclosure approaches (cognitive), belief that the individual will benefit from the knowledge (affective), capacity to ameliorate distress (affective) and the likelihood that a patient and or their family would be receptive to it (situational). The theory of planned behaviour seeks to model these concepts to explain their relationships [101].

The ability of an individual to perform a particular behaviour is associated with their understanding of how much control they have over performing that behaviour or how "easy" they find it, which is in turn congruent with their concept of self-efficacy. Self-efficacy or perceived behavioural control [41] can be the perceived level of confidence a GP has in being able to achieve a given goal [40] and the impact of this perception on, and intention to act or actual behaviour. In the case of undertaking or disclosing a dementia diagnosis, the goal may be disclosure, but it may also be that the recipient understands and accepts their condition, or how they might respond to disclosure. Whether a person performs a behaviour then is also determined by the potential response of others to the behaviour. Thus, while the action of disclosure may be "easy ", the context and situational components can impact on confidence to achieve the "desired" goal. Therefore, the likelihood that a particular behaviour will be achieved is linked to the ease or confidence an individual has in their ability to achieve it and the perceived or actual response of others to the behaviour or action. While a GP may have the confidence to undertake a diagnosis and disclose that diagnosis, if the patient is perceived as responding negatively to the disclosure, the GP may delay or not undertake disclosure.

#### Measuring Attitude and Confidence

Attitude scales are developed to establish people's judgements about the object of an attitude. While attitude scales are intended to be generalised measures of an attitude towards something, in this case I am interested specifically in GP attitudes towards the diagnosis, treatment and management of dementia, not a general attitude towards dementia or people with dementia per se. Unlike attitudes, confidence is not a generalised construct but is situational and task specific and refers to one's perceived capability to undertake a specific task or behaviour – it is a judgement of capability [40, 136, 137]. We were interested in the perceived capacity of GPs to diagnose, treat, manage, and provide referrals to patients with dementia. As such, confidence scales asked a set of questions that ask a respondent about the extent to which they feel confident undertaking specific tasks, in this case those skills or tasks related to the diagnosis, treatment and management of dementia. As with the development of attitude scales, confidence is measured by totalling the scores of each item to indicate overall confidence, with a higher score indicating greater confidence.

Several tools have been employed to measure either knowledge, attitudes, and to a lesser extent confidence as they relate to the diagnosis and management of dementia. However, there appear to be no validated survey instruments used across multiple studies and few have been employed to measure the effect of dementia education on confidence and attitudes using a validated and reliable instrument. In relation to dementia education programs, which attempt to overcome attitudinal and confidence deficits by increasing clinician knowledge, no attempt to measure changes by surveying prior to and after an intervention have been undertaken.

For example, Giezendanner et al [111] conducted a cross sectional study of GPs using a survey designed to measure attitudes towards early diagnosis. Exploratory factor analysis was undertaken to establish themes in the data, identifying both enablers and barriers to care. Enablers included improving disease outcome, delaying institutionalisation, enabling planning for the future support and care, and making appropriate legal arrangements. Barriers included the burden of stigma, embarrassment or discomfort in disclosing a diagnosis, the lack of effective treatments, time constraints or increased suicide risk [111].

Liu et al [109] developed a tool using clinical expertise and a literature review to measure the attitudes of GPs towards managing dementia and comparing those with training against those without. Self-report was used to indicate whether training had been undertaken. Exploratory factor analysis revealed two themes; confidence and negative feelings, with GPs who had undertaken training feeling more confident and holding fewer negative feelings toward care than those who had not undertaken any training [109]. While respondents indicated that they had received training, the type or length of training was not disclosed.

Lathren et al [128] employed a pre-test post-test research design to measure the confidence of 29 GPs both before and six months after a one-day workshop on dementia screening, diagnosis and management. Descriptive results from this small study indicated that GPs felt more confident in their clinical skills, the provision of information and education to patients and carers, and the referral of patients to community resources via exposure to relevant local resources and groups. These results were evident six months after training along with an increased use of dementia screening and assessment tools [128]. While the sample size for this study was small and was reliant on self-reporting, results indicate that targeted educational interventions have the capacity to improve GP confidence in relation to clinical skills and communication with both patients and carers.

An Italian study utilising two questionnaires, (n=131), Veneziana et al [123] compared GPs' knowledge of, and attitude towards early diagnosis based on sex and time since graduation. Results indicated that tools to diagnose and manage dementia were not used by over half of the sample, training in early recognitions of signs and symptoms of dementia was inadequate and that confidence in diagnostic skills was low as a result [123].

A Singapore study [90], employing a mail out survey to 296 participants, assessed GP confidence and attitudes towards managing dementia. Results indicated that while GPs had a positive attitude towards early diagnosis, they lacked confidence in making the diagnosis themselves, as well as in communicating a diagnosis to the patient and managing dementia [90].

O'Connor et al [56] undertook a more thorough approach to the development of a scale to measure attitudes towards dementia, including exploratory and confirmatory factor analysis. The Dementia Attitude Scale (DAS) is a 20-item scale measuring 'Dementia knowledge' and 'Social Comfort', developed to reflect the affective, cognitive and behavioural components of an attitude [56]. The sample population comprised undergraduate (psychology and nursing) students. Goodness of fit statistics however, suggested a lack of fit between the hypothesised model and the data. While the study is useful in relation to understanding the underlying psychological structure of attitudes, it has limited utility in relation to the role of general practitioners in the diagnosis and management of dementia. There is also no attempt at the analysis of the relationship between confidence and attitudes and their respective impact on intended or actual behaviour. In addition, confidence is erroneously treated as a generalised measure, whereas it needs to relate to a specific behaviour [40].

Turner et al [30] developed a survey to measure knowledge, confidence and attitudes of GPs as it related to the diagnosis and management of dementia which was administered prior to an educational intervention (n=127). Results indicated that GP knowledge of dementia was limited, as was knowledge of local support services and resources. Confidence (based on two questions) indicated that confidence in making a diagnosis and managing dementia related symptoms was also low. Using a 10-item survey and employing exploratory factor analysis "a weak but interpretable factor structure" was developed that included the constructs *"heart felt"* (three items) and *"heart sink"* (four items) to describe GP attitudes towards dementia. Those who reported difficulty in diagnosing and managing dementia were less likely to hold positive attitudes towards early diagnosis. [30]. While the authors indicate that the proposed model was weak, they indicated that it exhibited clear face validity, however, no attempt was made assess the quality of the hypothesised factor structure or confirm the proposed model.

Kaduszkiewicz et al [39], utilising a postal survey, attempted to explore the relationship between a GPs' self-estimated competence and their attitude and approach towards dementia (n=210). The 'competence' index was created from the mean score of two items relating to clinical ability, while the mean score of four survey items measured general attitude. Results indicated that competence was strongly correlated with attitude, with those reporting a negative attitude toward caring for someone with dementia also reporting a lack of capacity to improve the life of patients with dementia [39]. While the study is useful for research focusing on the relationship between self-perceived competence and attitudes, the 'indices' employed are arbitrary with no exploration of the underlying structure of competence or attitudes from the survey data.

With the possible exception of O'Connor, no attempt has been made to develop a validated tool that measures the confidence and attitudes of GPs in relation to the diagnosis, treatment, and management of dementia to be used within the context of an educational intervention. While the above-mentioned surveys may provide us with insights into prevailing attitudes *vis a vis* dementia, from a number of populations, what they do not do, and what they were not designed for, is to measure the effectiveness of an educational intervention on the confidence and attitudes of participants that is both valid and reliable.

## Preparation for practice

GPs may not receive adequate training to equip them to manage dementia well. GPs have reported that they generally feel unprepared to diagnose and manage dementia for both patients and their families [78, 79]. Kellet et al [80] indicate that foundation doctors (GPR equivalent in Australia) felt unprepared for diagnosis and decision making and required greater practical opportunities to hone their clinical skills [80], while Miles et al [81] report that while graduates felt prepared for practice, less than half felt prepared to deal with neurological problems and diagnostic uncertainty [81]. General practitioners have minimum requirements for continuing professional development which include mandatory activities over a three-year cycle, addressing a broad scope of educational opportunities. Recent studies have indicated that approximately eighty percent of GPs have not received any form of dementia education in the last two years [31, 82]. While studies have identified a link between knowledge and confidence, Mullan et al [83] reported that- at a bivariate level - training and knowledge did not predict confidence, suggesting that in so far as confidence is concerned, other factors, such as exposure to, and experience with patients with dementia, may be at play [83]. In a recent study of student preparedness to practice, Miles et al [81] indicated that medical graduates required opportunities for participation (direct clinical experience) rather than observation, with real patients to garner the practical experience required in general practice [81].

## **Dementia Education**

It has been acknowledged since the early 2000's that dementia education for GPs should include greater epidemiological knowledge, strategies for communicating a diagnosis, management of behaviour problems, and an enhanced knowledge of social services provided for patients and their carers [114, 132]. Tullo [133] emphasises the importance of personhood, quality of life, and communication with patients [133], while Edwards et al [134] promote person centred care as an holistic, biopsychosocial approach to dementia care that should be incorporated into GP education sessions rather than a traditional biomedical focus on treatments and cure [134]. Phillipson suggests a focus on the slow progression of dementia and maintaining quality of life [135]. Moreover, Mullan, et al [83] indicate that an intention to implement person centred care predicted a greater level of confidence to provide care [83], and that in order to adopt person centred care a positive attitude towards people with dementia must be held.

Amindezadeh [107] suggests that educational interventions should target gaps in knowledge, skills, and attitudes, and include therapeutic solutions. Further, this author indicates that the inability to recognise early signs of dementia can be the result of many factors including of a lack of knowledge of the condition, therapeutic nihilism, stigma, ageism and deficits in communication, disclosure, and management [107]. To address these issues educational interventions have evolved from a largely biomedical focus, to one that views dementia as a complex, progressive and chronic condition that is responsive to timely, individualised, and comprehensive treatment and management plans. It has been reported that educational interventions which include active learning and participation in their design, contribute to improvements in detection of dementia in primary care [130] and that problem-based learning is more effective at increasing knowledge than lectures [131].

However, while these educational interventions appear to increase knowledge levels and confidence and there is some clarity about the recommended focus of such education, there is very little research concurrently examining the relationship between knowledge and the attitudes and confidence of GPs and provision of education.

Dementia educational interventions aim to bridge the gap between clinical knowledge and clinical practice by increasing the skills base of participants through providing information and increasing awareness and knowledge. For GPs, outcomes may include improved knowledge of the signs and symptoms of dementia and information on current therapies, tools available for assessment, and instructions on their use [7].

A perceived inability to provide effective treatments or improve the quality of life for someone with dementia has been identified as a common response by GPs to a dementia diagnosis and is more prevalent among those who had not undergone any form of dementia education [119, 120]. This finding is important because feelings of helplessness (the perceived inability to provide treatments to alleviate or cure the condition) may reduce confidence and hamper diagnosis and management of symptoms. In contrast, GPs who had participated in dementia education were less likely to feel helpless, and in doing so play a more active role in the management of their patients [121].

GPs report a desire to increase their knowledge and skills around dementia diagnosis and assessment. Robinson et al [122] note that dementia was an

important topic for GPs and that two thirds indicated interest in learning more about dementia care. Other research has also highlighted the need for more GP training and education around dementia [7, 107, 114, 123].

It has been established that GPs who have had prior education about dementia were significantly more likely to undertake cognitive assessments than those who had not [121], and that the active participation of GPs in the early detection of dementia can lead to better treatment, access to psychosocial and pharmacological interventions and potentially lead to improved cost-effectiveness [124]. Whether an individual benefits as a result of early diagnosis is difficult to ascertain. Many later diagnoses occur as the result of a clinical crisis, or event such as a fall, and it is difficult to evaluate whether provision of earlier support may have proved beneficial, particularly where these may be insufficient [9].

# Evaluating the effectiveness of education

There have been a broad range of educational tools and resources developed for the education of GPs in dementia. One such study by Lathren et al [128], using a pre-test post-test research design, established that GP confidence increased as a result of a one-day training program on dementia screening, diagnosis and management, and was still evident six months after its completion. Additionally, improvements were observed in perceived capacity to educate people with dementia and their family members, making appropriate referrals to community care and increased use of cognitive screening. However, the sample size for the study was small (n=29), especially for the post training survey. Therefore, caution must be applied when interpreting results.

Downs et al [23] compared three educational interventions intended to improve detection and management of dementia in general practice settings: an electronic tutorial carried on a CD Rom; decision support software built into the electronic medical record; and practice-based workshops. Results indicated that both decision support system software and practice-based workshops were effective at improving detection rates, but it was not clear from this study which intervention provided the greatest improvement.

In a postal survey of 414 GPs, Liu et al [109] found that GPs who reported having undergone training in dementia also reported having greater confidence in making a diagnosis and managing symptoms than those who had not, and that negative attitudes towards dementia care were more evident in the non-training group [109]. While this study relied on self-reported training and therefore, we cannot know what type of training was involved, or the level of experience of respondents, results suggest training may result in improved confidence toward dementia management. This concurs with results from the Lathren study, which demonstrated that training focusing on diagnostic and management skills has a positive impact on confidence and that training has a lasting impact on participants [128].

Pond et al [129], utilising a control intervention research design reported that the rate of correct diagnoses increased in the group which received an educational intervention, suggesting significant improvement in the identification of people with dementia as a result of the education. The intervention was undertaken by a medical educator and covered instruction on the use of dementia tests, dementia diagnosis and management based on Royal Australian College of General Practitioners (RACGP) guidelines and exploration of potential barriers to dementia diagnosis. The results for this study indicate that training targeting diagnostic and management skills has a positive impact on diagnosis rates.

## Dementia education in the Australian context of GP training

Clinical guidelines for the management of dementia in Australia emphasise the importance of timely diagnosis and raising the issue with the person and their carer as soon as symptoms emerge and a systematic approach to diagnosis be undertaken [92]. To enable this, training should focus on understanding symptoms and be approached from the position of person-centred care, and include attitude, knowledge and skills development [92]. Phillips et al [85] indicate that knowledge and skills deficits in relation to the diagnosis of dementia could be addressed by focusing on the benefits of early diagnosis, increasing awareness of guidelines and encouraging a structured approach to testing.

Within Australia, GP Supervisors play a pivotal role in the preparation and training of GPRs within a general practice setting. The knowledge, skills, and attitudes of supervisors role model engagement for GPRs with people presenting with potential symptoms of dementia. Therefore, GP Supervisors require not only the necessary skills and aptitude to fulfil the role of supervisor, but also need to demonstrate attitudes representative of best practice dementia care that are conducive to timely diagnosis and ongoing support of someone with dementia [127]. GPRs work as GPs in practice under the supervision and guidance of a GP Supervisor while undertaking training in several training modules delivered by regional training providers.

Curriculum for Australian general practice operates under a competency-based approach to education. Competency based medical education (CBME) involves training and assessment methods that provide a GPR with the requisite skills set that enable them to operate safely and effectively within general practice. CBME has five main domains of practice which include: communication skills and the doctor patient relationship, the application of knowledge and skills, population health, ethics and professionalism and organisational and legal requirements. Each of these objectives has a number of core skills attached and represent the fundamentals of best practice in Australia and are linked to learning outcomes that each GPR must achieve [125, 126]. Supervisors must ensure that the GPR is competent in professional practice to protect the patient from potential harm, monitor and evaluate performance and facilitate effective feedback to support continuing learning. The supervisor role entails three key elements:

- 1. Clinical guidance and support. This means being readily available to the registrar on site and if not, being contactable should the registrar require their assistance or guidance.
- 2. Performance review. This role entails reviewing the registrar's performance against goals set in their learning plan and their general development as GPs, as well as aiding in developing a learning plan, based on an assessment of their skills, experience and confidence.
- 3. Professional development. This role involves the GP Supervisor developing their own skills as a clinical teacher [125, 126].

Therefore, the role of the supervisor is to assist the registrar to develop a learning plan as well as providing clinical and other support during their training period. Supervisors facilitate learning through identification of learning needs, reflective learning, providing access to resources, providing advice on applying knowledge to specific cases and role modelling interactions with patients. Interaction with, and feedback from the supervisor provides the registrar with the reassurance, correction and guidance they need to develop their clinical and interpersonal skills [126]. The development of the General Practitioners Attitude and Confidence scale for dementia (GPACS-D) evolved as part of a larger program to raise awareness and educate general practitioners in the diagnosis, treatment, and management of dementia. An essential part of this project was the design, development, and application of survey a tool to measure the impact of educational workshops on attitudes and confidence levels of GPs in relation to diagnosing and managing dementia.

The GPACS-D was developed because of an absence, internationally, of a valid tool that measures GP attitudes *and* confidence in diagnosing, treating, and managing patients with dementia, and to determine change as a result of a dementia educational intervention.

# Aims of current research

1. Develop and test a preliminary tool to measure the attitudes and confidence of GPs towards the diagnosis, treatment, and management of dementia.

2. Refine and validate the tool including with confirmatory analysis. Further, undertake a comparative analysis of GP participants to test the efficacy of the tool in relation to group differences and in measuring the confidence and attitudes of GPs as it relates to the diagnosis, treatment, and management of dementia.

3. Employ the validated survey to measure the impact of dementia education workshops on confidence and attitudes of GPRs and GP Supervisors.

Identifying the determinants of confidence and attitudes provides insights from which curriculum can be developed that specifically targets any deficits GPs possess in relation to confidence and attitudes towards dementia. Having a reliable and valid tool for measuring confidence and attitudes allows the measurement of the impact of any targeted education on workshop participants.

# Chapter 3 - Method

# Introduction

The Recognising, Diagnosing and Managing Dementia in General Practice Workshop is a national project. Developed by the Wicking Dementia Education and Research Centre, it was designed to improve both the awareness and knowledge of dementia of GPs and GPRs as well as their attitudes towards the diagnosis and care of dementia patients (discussed in detail below) and increase capacity to both diagnose and manage dementia.

Two tools were used to assess the effectiveness of the workshops: The Dementia Knowledge Assessment Scale (DKAS) and the GPACS-D. The DKAS [203] is a validated tool that was used to measure knowledge of dementia at baseline and after the educational intervention and to assess knowledge change as a result of the workshop [31].

While the DKAS could be employed to measure knowledge, there did not appear to be a suitable tool that could measure GP attitudes and confidence in relation to the diagnosis and care of someone with dementia within a pre-test post-test scenario. Therefore, the primary task of this research was to develop a valid and reliable tool that would complement the use of the DKAS to gain a fuller understanding of the relationship between knowledge, confidence, and attitude, and ultimately the effectiveness of an education intervention in supporting GPs to develop the capability to effectively diagnose and manage dementia.

The literature reveals several questionnaires and surveys exist that address confidence and/or attitudes of practitioners in managing dementia in general practice. These studies informed the development of a preliminary list of items, used to explore the attitudes of GPs towards diagnosis and care, as well as perceived self-efficacy with regard to the clinical skills required to both diagnose and manage dementia [90]. However, these instruments were not fit for purpose because they were not developed to measure the impact of an educational intervention on the confidence and attitudes of GPs.

Other studies have been conducted to suit a particular research purpose, either to identify barriers to diagnosis, explore relationships between attitudes and confidence, or to establish differences in attitudes between different professional groups or those with prior training against those without.

For the most part analyses have been undertaken at item level rather than via the use of scales, and where the grouping of individual items to measure either attitudes or confidence has been undertaken, they have not undergone any thorough assessment of reliability or validity. Additionally, very few have been used within a workshop context to measure confidence *and* attitudes at baseline and after an educational intervention.

Therefore, the major purpose of this research was to develop a valid and reliable tool that (a) measures the attitudes and confidence of GPs towards the diagnosis and treatment/management of dementia and (b) can be used to measure the impact of an educational intervention on attitudes and confidence that can be used to inform future development of workshops aimed at improving service delivery within a general practice setting.

The development of the GPACS-D involved three distinct stages which are reflected in each published paper and which are described in this chapter:

- Paper 1: Develop and test a preliminary tool to measure the attitudes and confidence of GPs towards the diagnosis, treatment, and management of dementia.
- Paper 2: Using confirmatory analysis, refine and validate the tool. Further, undertake a comparative analysis of GP participants to test the efficacy of the tool in relation to group differences and in measuring the confidence and attitudes of GPs as it relates to the diagnosis, treatment, and management of dementia.
- Paper 3: Employ the validated survey to measure the impact of dementia education workshops on GPs and GPRs.

# The research team

The research team oversaw the development of the program and acted as the expert panel in the development of the GPACS-D. Use of a panel of experts is common practice in survey development [138] whose primary task is to establish face and content validity. These individuals were selected due to their knowledge and experience of working with people who have dementia, medical educators, curriculum development or delivery, and/or their expertise in scale development.

# Author role

The Author's role was to (a) review the compiled list of items, (b) undertake the literature review, (c) collate potential survey items, (d) conduct the focus group, (e) conduct tests of reliability, (f) undertake the pilot study, (g) undertake statistical testing, (h) conduct the exploratory factor analysis, (i) conduct confirmatory factor analysis, and (j) undertake all analyses associated with each of the above tasks.

# Participants, Sampling and Recruitment

Participants involved in the item content and construction stage were recruited via local training and organisational networks (Table 3-1), while purposive sampling was employed to recruit GPRs and GP Supervisors participating in the workshops. Those attending Identifying, Diagnosing and Managing Dementia for GPs workshops (detailed in Table 3-7), were informed of the voluntary nature of the survey and provided with an information sheet and a consent form to complete if they wished to participate. A University Human Research Ethics Committee reviewed and approved the study (Reference number; H0012046).

STAGE OF RESEARCH	Participants	Approach	Sample size
Stage 1 - Tool development			
Focus Group	GPs	Invitation - networking	12
Test retest	GPs and medical students	Invitation - networking	55
Pilot Study	GPRs and GPSs	Purposive sampling methods*	207
Stage 2 - Tool confirmation			
Confirmatory Factor Analysis	GPRs and GPSs	Purposive sampling methods*	194
Stage 3 - Tool application			
Survey administration to measure effectiveness of educational intervention	GPRs and GPSs	Purposive sampling methods*	446

Table 3 -1 – Partici	nant and sampling	method for develo	nment of the GPACS-D
	pant and sampling	method for develo	

\*While purposive sampling was employed, completion of the survey was voluntary.

# **Research design and method**

A quasi-experimental research design employing pre-test post-test method was used to establish the impact of a dementia educational intervention on participants.

Qualitative techniques in the form of a review of the literature, focus groups and the use of an expert panel were used to develop an original set of survey items and to establish face and content validity.

Quantitative techniques were used to establish test-retest reliability, the sensitivity of the tool to difference, the identification of potential constructs, validation of the hypothesised constructs as well as gauging the impact of a dementia educational intervention on each group of GPs at baseline and after a dementia educational intervention (see below).

The establishment of a control group for comparison with the workshop group to establish whether unknown internal or external factors may have affected the results was discussed, and while a control group would have been desirable, it was rejected because of the difficulty in not only recruiting but also retaining GPs in the study [139]. Studies have also indicated that while a large majority of GPs were in favour of general practice research only 58% had participated with a similar proportion indicating they would not do so in the future [140], while another study described the difficulties recruiting GPs for studies and the low response rates achieved using a variety of recruitment methods [141], while an Australian study reported a recruitment rate of between 4% and 6% [142].

The proposed method follows accepted precedents in the development of surveys and uses several methods to identify item content including the use of expert panels and literature reviews [143]. Face and content validity can be assessed using both expert panels and those individuals representative of the population being surveyed using either/or cognitive interviewing and/or focus groups.

The use of test-retest methods in the pretesting phase establishes the reliability of items, while the pilot study was employed to assess sensitivity to change for individual survey items, both within and between groups. Lastly, the development and validation of potential constructs or factors was undertaken through the employment of exploratory and confirmatory factor analyses [143].

Table 3 - 2 Process Summary

Survey stage	Participants	Purpose
ltem	Expert	Establish face and content validity of survey
construction	Panel (n=6)	items.
Focus Group	Medical	Establish construct, face, and content validity
	educators	of survey items.
	(n=12)	
Test retest	GPs and	Assess reliability of survey items.
	Medical	
	students	
	(n=55)	
Pilot study	GPs and	Assess sensitivity to change for each survey
	GPSs	item.
	(n=207)	Development of preliminary model.
Confirmation	GPs and	Assess construct and discriminant validity of
	GPSs	preliminary model.
	(n=194)	
Administration	GPs and	Assess utility of the tool via comparative
	GPSs	analysis between GPRs and GPSs.
	(n=446)	

# **Development of survey items**

Potential items were initially drawn from existing questionnaires (see Table 3 - 3) developed in Europe [30, 38, 112], used to measure GP attitudes towards the diagnosis and treatment of dementia. A trial questionnaire had previously been used but not published to evaluate a dementia education intervention but after trialling, shortcomings became apparent. The original questionnaire items were subject to a review of their suitability for inclusion in a survey intended to measure differences between groups and the effectiveness of educational interventions. This review revealed that several items in the original questionnaire were inappropriate for use within a short educational intervention (see below) and did not address confidence in clinical capacity.

Rating (please tick)						
Statement	1					6
	Does not apply at all	2	3	4	5	Applies very well
<ol> <li>As a GP I cannot do anything to improve the quality of life of patients with dementia +</li> </ol>						
<ol><li>Caring for patients with dementia is a rewarding task for me as a GP</li></ol>						
<ol><li>I feel helpless in the relationship with my demented patients</li></ol>						
<ol> <li>I would prefer to have nothing to do with the care for dementia patients *</li> </ol>						
5. Early detection of dementia benefits the patient *						
<ol> <li>Early detection of dementia has no therapeutic consequences *</li> </ol>						
<ol> <li>I actively search for dementia in all patients over 65 years of age *</li> </ol>						
<ul> <li>8. In case of a suspicion of cognitive</li> <li>problems I regularly use cognitive tests</li> <li>*</li> </ul>						
9. I suggest to relatives of patients with dementia that they contact Alzheimer's Australia						
10. I suggest to the relatives that they participate in a self-help group *						
11. I propose the relatives often help in organising the care (e.g. in finding a legal guardian)						
12. In my opinion the relatives have excessive communication needs *						
13. As a GP/Nurse I can help relatives with burden of care quite well						
14. Guidelines for the diagnosis and treatment of dementia would help me						
15. I would like to participate in training on how to deal and speak with dementing patients and their relatives.						

# Table 3 - 3: Questions drawn from existing questionnaires.

16. Disclosing diagnosis and prognosis does more harm than good to the patient *+			
17. Most patients are grateful when I address their cognitive decline *			
18. Patients react with shame when their cognitive deficits are addressed *			
19. When communicating the diagnosis to the patient I never use the term 'dementia' +			
20. When communicating the diagnosis to the patient I never use the term 'Alzheimer's' *			
21. I only disclose when the patient demands it *			
22. Patients with dementia should be informed early because of the possibility of planning their lives *			
23. I inform the relatives in more detail than the patient on the course of the disease *			
24. When addressing the relatives, I avoid the true diagnosis and I prefer to use terms like 'senility' or 'vascular problems' *			

\*Indicates the source of the item was Kaduszkiewick [39]

+ Indicates the source was Turner [30]

The primary source of items emanated from Kaduszkiewick\* [39] (15 items), and Turner+ [30] (3 items). The remaining 7 items (items 2,3,9,11,12,14,15) were developed by a research team. The source questionnaires used to inform the primary content of the original list of items were originally administered as part of an ad hoc study [39], while those sourced from Turner were administered prior to an educational intervention [30]. In the context of the workshop evaluation the survey was required to be used in different settings and as part of a pre/post-test research design. An examination of the items originally considered for the survey demonstrated that they were not specific to attitudes and confidence toward dementia. Further, some questions were not suitable for a pre-test post-test research design (e.g. items 14, 15, 17, 18, 21). In total, over 13 items were considered unsuitable for a pre-post design.

An additional number of the items were behavioural (items 7, 8, 9, 10, 11, 13, 23, 24). That is, they ask people what they do as opposed to what they think (e.g. I

actively search for dementia in all patients over 65). Research indicates care must be taken not to combine behaviours with affective responses because items need to be consistent in what they are measuring – they should only measure a single issue [144]. Additionally, there are problems associated with asking people to indicate a change in behaviour after a 3-hour workshop, given that they have not had the opportunity to put learning into practice and given this, indicators of behaviour change were inappropriate for the intended application of the tool.

Unsuitable items were eliminated at this stage of the process. The remainder (items 1,2,4,5,6,16,19 and 20) were retained and edited to reflect an attitude towards diagnosis, prognosis, treatment, or management of dementia. This was achieved via editing of each of the items which were then sent to each member of the research team for comment and editing. Once feedback had been received and survey items amended accordingly the 'final' set of items was sent to each member for approval.

The intent of the proposed tool was to measure the attitudes and confidence of GPs towards the diagnosis, treatment and management of dementia in an instrument that could be used within a workshop and was both reliable and valid – i.e., it measured what it purported to measure and that it did so reliably. Both the surveys used to develop the original questionnaire and the questionnaire itself had not been assessed for reliability and validity. As such, in its original state, the questionnaire being used to evaluate the workshops was limited to descriptive analyses at item level rather than via subscales, whose scores are considered more reliable than those for individually observed variables [145]. Considering this, the current tool could be best described as a questionnaire rather than survey because it contained individual items, not subscales which are more appropriate for research that is ongoing or used in different research settings such as dementia education workshops.

This review led to the decision to rewrite the survey to provide not only a baseline (one off) measure of the attitudes and confidence of GPs in relation to the diagnosis, treatment, and management of dementia, but also a tool that could be used within a pre-test post-test situation, such as educational workshops.

## Generation of GPACS-D preliminary survey items

The selection of individual survey items for the new survey was based on the key learning objectives for GPs which comprised, 'recognition and awareness'; 'diagnosis and management'; 'capabilities and confidence'; and 'referrals,

resources and support', and reflect those areas which are considered important in the diagnosis and management of dementia [7]. A list of potential survey items was generated from reworking some of the original items contained in the first questionnaire so that they reflected an attitudinal declaration. Some survey items were taken from existing questionnaires [12, 30, 39, 56, 63, 108, 146], while others were developed from literature. Additional survey items were selected on the basis that they expressed an attitude or perceived confidence relative to the diagnosis and treatment of dementia, reflected the content of the workshop, and utilised research that focused on barriers to diagnosis or obstacles to diagnosis and care [7, 147], and were included from both quantitative and qualitative studies. This pool of items was then refined, focusing on question construction and the appropriateness and relevance of the questions as per the workshop objectives.

The initial list of survey items were sent to the expert panel for critical review and refinement, focusing on question construction, interpretability, and relevance. Editing and refinement of survey items was iterative and achieved by sending successive versions of the draft instrument to each member of the project team for feedback.

Prior research in survey design and structure provided the basis from which to proceed with survey construction. No definitive rule exists as to the number of items that describe a construct or that combine further to constitute a scale, with the number dependent in part on the complexity of the scale [143]; however the scale should be both internally consistent and parsimonious so that a minimum number of items adequately define each construct of interest [144]. While the number of items per construct or scale depends on the complexity of the construct being measured, a construct should comprise between three and six statements [143, 144] but at the initial stages of survey construction more should be included because problematic items identified during the developmental stage can be eliminated for statistical or methodological reasons [10]. Based on these observations we undertook to generate six items per workshop objective (construct) based on the assumption that some items would be eliminated during the survey development process.

The length of the survey was based on literature suggesting that six to ten minutes was an acceptable time to complete a survey, with longer completion times having the potential to result in respondent fatigue and the introduction of error. Thus the rule appears to be the shorter the time taken to complete a survey the less likelihood of respondent fatigue, missed questions and reduced measurement error because respondents are less likely to misread or skip questions as a result [138]. Focus group results indicated that it took approximately 10 minutes to complete the survey which was deemed an acceptable timeframe.

This rationale was also applied to the construction of items. Keeping questions short and simple, avoiding complex wording, technical terms, jargon (unless the population being surveyed is familiar with such terms) and the use of language commonly used by the respondent(s) [148] were the main considerations in the development of survey items. These considerations help ensure that respondents read shorter lines more accurately and skip fewer words, understand what the question is asking and increases ease of use. If respondent finds a survey easy to read, follow and complete, the response rate will improve and error will decrease [149].

## Generation of ratings scale

Scales are a collection of items which are scored and combined to yield a scale score [148]. Attitudinal scales are a set of statements that seek to establish people's judgements about the object of an attitude (e.g. attitude towards dementia diagnosis and management). An attitude cannot be directly measured with a single variable, therefore, while we may not be able to directly measure attitude (it is a latent construct, that is not directly observable), we can measure whether attitudes are positive or negative using a group of variables. Therefore, in measuring attitudes towards diagnosis and care we might employ statements around the benefits of diagnosis, the utility of treatments and external supports. It is the total score from each of these items that provide us with an indication or a measure of attitudes towards care. Ultimately the aim is to develop a set of items that clearly represent the construct [138].

The general rule is that the more response points on a scale the better because it provides greater variability of responses. The number of response points is typically between four and nine [143]. Research on the efficacy of the number of points is equivocal but suggests that 5-point scales yield higher quality data than 7 to 11 points [150, 151], while other research suggests no difference [152]. Despite these differences the general consensus appears to be that the use of five to seven point scales yield higher quality data than fewer points and are more practical than longer scales, with 5-point scales being the most popular [143].

The original 6-point ratings scale was replaced by a 5-point Likert ratings scale comprising verbal anchors of strongly disagree, agree, neutral, agree and strongly agree which is commonly used in in scale tools [143]. There is a lack of consensus surrounding the use of even numbered scales with arguments presented for and against their use; however, odd numbered ratings scales are more common than even numbered ratings scales [143]. Even numbered scales are commonly used to force respondents to take a position (either positive or negative), especially if there is a preponderance of neutral responses [143], while odd numbered scales on the other hand accept that respondents may not have a view (are neutral) or are unsure and are entitled to express a neutral view. Based on these arguments a decision was made to use a 5-point scale, not only because we accepted the argument that respondents may not have a view or are unsure about the item in question but also a scale any larger would impact negatively on the format of the survey and had the potential to make the survey crowded and complex. Research in survey design has suggested that surveys should contain "white space" so that items are seen to be clearly separate and response categories easy to identify and complete [149].

## **Evaluation of preliminary scale**

A tool that aims to measure attitudes and confidence within a pre-test post-test research scenario needs to be both valid and reliable. To assess these criteria several procedures need to be undertaken to assess the extent to which the tool measures what it purports to measure and can do so in a reliable manner.

#### Evaluation of face and content validity

Respondents should be the guide when designing a survey and therefore the question or item should represent the perspective of the respondent [153]. Following the completion of the draft survey, pretesting was conducted to establish face and content validity and included the use of a focus group and a panel of expert respondents to enhance item clarity. Both are common means of establishing face and content validity [154].

Two possible methods were considered to assess the face and content validity of the survey: cognitive interviews and focus groups. Cognitive interviewing entails face to face interviewing that utilises a 'think aloud' approach and probes to identify the thought process of respondents in answering survey items from which insights can be gained in relation to item construction and wording [150]. Typical aims of cognitive interviewing include whether the respondent understands the question/item, whether the response category is appropriate or whether rephrasing the question adds clarity [154, 155]. Given the time it takes to recruit and undertake individual cognitive interviewing (studies indicate between 30 to 40 minutes per interview), focus groups were employed because they can gather the same type of information as cognitive interviewing and are recognised as an effective means of gathering greater amounts of data in a more efficient time frame. In combining focus groups with survey development participants not only assist in item generation and refinement of items relevant to the survey population but also augment pre testing of preliminary items [156].

#### Focus group

The focus group comprised a convenience sample of 12 GPs (Medical Educators), representative of the population for whom the survey was designed and administered. The format of the focus group consisted of introductions and a brief overview of the project and the purpose of the focus group. Participants were asked to complete the draft survey and provide written comment on item construction, appropriateness, relevance and content scope [155] and to write their comments in a space provided below each statement (see Table 3 - 4). Group discussion revolved around the potential ambiguity of items, any confusion because of reading the statement and any that were difficult to answer. Suggestions for the rephrasing of items was also addressed in the discussion, with respondents encouraged to write their suggestions in the space provided directly below. Results from the focus group were collated and sent to each member of the expert panel (n=8), with feedback incorporated into the survey and sent back to each member for further feedback until the survey was deemed ready for piloting.

# Table 3 - 4: Proforma used for focus group

## Confidence and Attitudes Towards Dementia Survey

Please read the following statements carefully. Once you have read each statement, please circle the number on the scale that corresponds with your answer between 1 and 5, where 1 is 'strongly disagree' 3 is 'neither agree nor disagree' and 5 is 'strongly agree'.

	Stro Disa	Strongly Disagree		Strongly Agree	
<ol> <li>Much can be done to improve the quality of life for people with dementia.</li> </ol>	1	2	3	4	5
Comment:					
<ol><li>I prefer to have nothing to do with the care of dementia patients.</li></ol>	1	2	3	4	5
Comment:					
3. The early detection of dementia benefits the patient.	1	2	3	4	5
Comment:					
4. It is important for relative/family carers of people with dementia to seek external support (e.g. counselling/support groups).	1	2	3	4	5
Comment:					
<ol> <li>Relatives/family carers of patients with dementia should be encouraged to contact Alzheimer's Australia.</li> </ol>	1	2	3	4	5
Comment:					
6. GPs are in the best position to help relatives/carers with organising care for someone with dementia.	1	2	3	4	5
Comment:					
7. I fear a communication of dementia will damage the doctor patient relationship.	1	2	3	4	5
Comment:					
8. Guidelines for the management of dementia would greatly assist in providing patient centred care.	1	2	3	4	5
Comment:					

	Strongly		Strongly		
	Disa	Disagree		Agr	ee
9. The term 'dementia' should be avoided when discussing a diagnosis with a carer/family member as it is likely to cause emotional distress.	1	2	3	4	5
Comment:					
10. Patients with dementia should be informed early so they can plan for the future.	1	2	3	4	5
Comment:					
11. It is important to inform the person with dementia of the terminal course of the disease.	1	2	3	4	5
Comment:					
12. It is important to inform the relatives/family carers of the person with dementia of the terminal course of the disease.	1	2	3	4	5
Comment:					
13. I feel frustrated because I do not know how to effectively treat people with dementia.	1	2	3	4	5
Comment:					
14. I feel confident in my ability to discuss legal issues associated with a diagnosis of dementia.	1	2	3	4	5
Comment:					
15. I feel confident in my ability to diagnose dementia.	1	2	3	4	5
Comment:					
16. I feel confident in my ability to communicate a diagnosis of dementia to a patient	1	2	3	4	5
Comment:					
17. I feel confident in my ability to provide appropriate medical care for a person with dementia.	1	2	3	4	5
Comment:					
18. I feel confident in my ability to provide advice about managing dementia related symptoms.	1	2	3	4	5
Comment:	-				
19. I feel confident in my knowledge of local resources to assist families/carers caring for a person with dementia.	1	2	3	4	5

	Strongly Disagree		Strong Agree		ongly ee
Comment:					
20. A geriatrician review is essential in any definitive diagnosis of dementia.	1	2	3	4	5
Comment:	-				

Any additional comments:

## Assess reliability

In order to conduct reliability testing a sample representing the population for which the survey was intended was required. A pilot population comprising GPs and final year medical students was used to evaluate the test-retest reliability of the proposed survey, with two weeks elapsing between the first and second administration, and no intervening education (see Chapter 5 for more detail).

Test-retest involves multiple administration of a survey to the same respondents to assess the instrument's reliability and consistency [157]. A weighted Kappa (k) coefficient was used to provide a measure of test-retest reliability for each of the individual items contained in the GPACS-D with a period of 2 weeks elapsing between T1 and T2 administration. Weighted Kappa is appropriate for use with ordinal data and is equivalent to the intra-class correlation coefficient [158]. A weighted kappa was used because it considers the magnitude of any discrepancy between T1 and T2 responses unlike the unweighted kappa which treats all disagreements equally regardless of the size of the discrepancy [159, 160]. The weighted kappa then is a more rigorous measure of reliability than the unweighted version. The following have been identified as standards for strength of agreement for Kappa coefficients: 0 = (poor'; .01-.20 = (slight'; .21-.40 = (fair'; .41 to .60 = .60)'moderate'; .61-.80 = 'substantial'; .81-1.00 = 'almost perfect' [24, 25]. A Kappa coefficient above .40 was selected as the cut-off for item selection as suggested by Fleiss et al [159]. Expected and observed agreement levels are also reported. Items with a Kappa coefficient above .40 and an observed agreement score of 90% or better were deemed reliable [161] and retained, while items scoring below any of these criteria were excluded.

## Pilot study to assess sensitivity to change

To have confidence in the accuracy of a tool it must be able to differentiate between groups, be sensitive to change and consistently or reliably do so. As mentioned above we used a weighted Kappa statistic to assess the extent to which each of the survey items were reliable and *stable* over time, while a Wilcoxon's signed ranks test was employed to assess sensitivity to change via the identification of any significant differences between pre and post workshop scores. We needed to be confident that each of the items contained in the tool accurately and reliably measured attitudes and confidence as well the impact of an educational intervention.

A process of item evaluation and reduction was undertaken through an examination of pilot responses to ensure that only the most discriminating and unambiguous items were included in the scale. In order to undertake this task, we required a sample of individuals for whom the survey was intended, in this case GPRs and GP Supervisors (refer to Chapter 5 for more detail).

A Wilcoxon signed ranks test for paired samples was undertaken to identify significant differences between survey item scores obtained from the pilot study to assess each item's sensitivity to change (a measure of construct validity) following an educational intervention (dementia workshop). A Wilcoxon signed ranks test is a non-parametric measure that is appropriate for use with ordinal data or where assumptions of normality are not met and has been shown to be preferable to the equivalent t test where these assumptions are not met, regardless of sample size [162]. Items exhibiting a non-significant difference between pre- and post-education administration were identified as potential candidates for elimination.

## Analyse preliminary data - principal component analysis

Principal component analysis (PCA) was employed to reduce the set of observed variables to a smaller, more interpretable structure and to identify potential constructs for further examination and refinement prior to further validation (see Chapter 5) [145, 163-165]. PCA is an exploratory technique used to reduce a large data set to more manageable format, or where no structure is apparent, or where the survey was developed in the absence of theory and is usually performed early in the research process to consolidate items (components) and generate hypotheses about underlying processes and is associated with theory development [145]. Because no specific theoretical model was used in the initial

survey development stage and because the development of survey items was an exploratory exercise, we employed PCA to identify any underlying structure in the data from which to generate hypotheses.

The alternative to PCA is exploratory factor analysis (EFA) and there is much debate surrounding the utility of EFA versus PCA in identifying potential structures in a data set. Both are exploratory techniques but differ in relation to the way each group variables. With EFA only shared variance is analysed while in PCA all variance is analysed. Both are concerned with identifying variables in a data set that form coherent subsets that are relatively independent of each other [145]. Variables that correlate with one another but not to other subsets of variables are combined into components or factors, which reflect underlying structures that create the correlations among variables. Proponents of EFA argue that because PCA is not computed with regard to underlying structure caused by the latent variable (the factor), it lacks validity [163], further arguing that rarely do researchers collect data without some sort of idea of how variables are related and that EFA is used to identify factors that cause the relationship among variables that comprise the factor and which causes the variables to covary [166].

However, as Tabachnick [145] points out, most items collected reflect a first guess that might prove useful and may or may have not been chosen with potential underlying processes in mind, and is performed in the early stages of research to consolidate variables and generate hypotheses about underlying processes for later confirmation by confirmatory factor analysis (CFA).

Although PCA and EFA differ in the way they analyse variance, they do not produce significantly different results or conclusions [167]. Further, Velicer et al [168] argue that while proponents of EFA cite the algebraic differences between each method to highlight the difference between the two, results from both indicate that they typically produce the same results and that any discrepancies rarely if ever have any practical importance. Further, they argue that defining PCA as exploratory and EFA as confirmatory techniques as competitive is unfortunate and that they would be better viewed as complementary.

Similarly, Tabachnick and Fidel argue that most studies employ a mixture of exploratory and confirmatory techniques, with exploratory appropriate at the initial stages of research or after the rejection of a theory [168], and that exploratory techniques should be employed except where a well-defined theory exists. Indeed, they further argue that PCA, as an unrestricted procedure, reduces

researcher bias because confirmatory approaches attempt to fit a preconceived model to the data and therefore risk confirmatory bias as a result of the failure of the researcher to specify the *best* model [168].

Because we collected variables of interest without recourse to any specific theory, and even though we assumed that the attitudinal and confidence related variables would correlate with each other we were not sure how they would group, therefore PCA, as an exploratory method, was deemed appropriate to use to generate potential themes which could be confirmed later through CFA.

Three criteria must be met before conducting a PCA: the sample must be large enough to undertake the analysis and the correlations between each item must be sufficient (>.30) [145, 165], the data needs to be 'factorable'. The factorability of a data set means that the data set should include groups of variables that significantly correlate with each other, since the aim of PCA and EFA is to identify components or factors within the data set. Initially this is done by an examination of the correlation matrix, noting the bivariate relationships between variables where correlations should exceed .30. If they do not, then PCA or EFA is unlikely to produce a model [145].

Sample adequacy was confirmed using the Kaiser-Meyer-Olkin (KMO statistic) where a minimum value =>.6 is required [145], while the factorability of the data were assessed using Bartlett's test of Sphericity (test values must be significant at alpha <.05). To assess the utility of each individual variable, communality scores were examined, with a low communality score indicating that the item is unrelated or has little in common with other items in the data set [165]. This is important because each of the items that comprise the construct need to be internally consistent, that is, the items measure the same construct and are interrelated.

Where a communality score <.30 was observed, the item was eliminated from the analysis [163]. Additionally, any item with a factor loading of less than .30 was also eliminated from the analysis, as were variables that cross loaded on factors. Small factor loadings indicate that the variable lacks utility (it contributes little to the factor or model), while cross loadings indicate that the item is not unique to a single factor and may be the source of multicollinearity between factors, which is undesirable because we want each factor to be distinct from others (even though it is rare for factors to be totally unrelated in the social sciences) [165]. Any items that failed to reach the critical values described above were eliminated at this

stage of the analysis with the PCA being re-run to produce a final factor solution. The results from this process are detailed in Chapter 5.

The number of factors in the model was established by examining eigenvalues and scree plots. Eigenvalues represent the amount of variance explained by an item, with values >=1 indicating that a substantial amount of variation is explained by the factor [165] and provides an indication of the potential number of factors in the model [145]. An examination of the scree plot (eigenvalues plotted against factors) also provides a visual display of the number of factors contained in the model and is outlined in Chapter 5.

Varimax rotation was used because we expected each of the factors to be unrelated, therefore orthogonal rotation was considered the most appropriate and it also produced the most interpretable structure compared to other rotations [145]. As mentioned in the previous chapter attitudes reflect a judgment about the object of the attitude, while confidence (or self-efficacy) is the perceived capacity to undertake a specific task, behaviour, or activity, therefore we expected these concepts to be independent of each other. Further, varimax rotation attempts to load a smaller number of variables highly on each factor resulting in more interpretable factors [165].

Elements of behavioural theory were used to interpret the results of a principal component analysis, borrowing elements of Ajzens' 'theory of planned behaviour'[101], especially as regards the influence of attitudes on an intention to act or actual behaviour, while perceived behavioural control or self-efficacy (commonly referred to as confidence), was informed via both Ajzen and Bandura's 'social cognitive theory' [40]. Both these theories have been used extensively in the health literature to examine and explain health behaviours of both individuals (lay people) and health care workers [169].

As a result of the above process the original 24-item survey was reduced to 20 items comprising four interpretable factors: *Attitude to Care, Confidence in Clinical Abilities, Engagement* and *Attitude towards Communication* (see Table 3 - 3).

Finally, tests of internal consistency utilising a Cronbach's alpha ( $\alpha$ ) value were calculated for each of the potential sub scales indicated by the PCA, the results of which are contained in Chapter 5. Internal reliability measures the extent to which items are measuring the same construct and refers to the interrelatedness of the items that make up the construct. While Cronbach's alpha is a popular measure of internal reliability it has attracted some debate. Cronbach's alpha is dependent on
the number of items that comprise the scale so that the more items the larger the alpha and therefore it is possible to get a large alpha and not be reliable [170, 171]. Further alpha has been used as a measure of unidimensionality or item homogeneity; that the tool measures one underlying construct, yet moderate to high alphas can be obtained from a set of items that are not unidimensional [172] and a high Cronbach's alpha can be obtained with two moderately correlated factors and two uncorrelated factors [172]. As such Cronbach's alpha should be used with caution as the number of items increases the reliability of the construct regardless of the homogeneity of items [170].

#### Confirmatory factor analysis - verification of preliminary constructs

While PCA provides a preliminary factor structure it does not provide an indication of the construct or discriminant validity of the tool, therefore confirmatory factor analysis (CFA) was undertaken to measure both the extent to which the hypothesised structure identified via PCA fits the data as well as assessing construct and discriminant validity (detailed in Chapter 6). Construct validity refers to the extent to which items comprising a factor are distinct from other factors, while discriminant (or divergent) validity assesses the extent to which each of the factors are unrelated to each other. CFA is commonly used to assess both construct and discriminant validity. While PCA might be described as hypothesis generating, CFA is hypothesis confirming or theory testing, that is, how well the hypothesised model fits the observed data [145].

Parameter estimates were examined to establish utility, while potential item misspecification was identified through an examination of the standardised residuals (values >1.96) and modification indices (values <.30) [163, 173, 174]. A suite of goodness of fit statistics was also employed to establish model fit and the construct and discriminant validity of the hypothesised model (see Chapter 5).

Because estimation procedures are dependent upon the distribution of the data, an analysis of data properties was undertaken to establish the extent to which data were normally distributed. Skewness tends to impact on tests of means while kurtosis severely effects tests of variance and covariance upon which CFA is based [163]. Therefore, evidence of multivariate kurtosis is of concern when conducting a CFA and making decisions about the type of estimation procedure to be employed. In relation to maximum likelihood estimation (ML) the  $\chi^2$  result is generally inflated as a function of multivariate non normality [175, 176].

While data were highly skewed and kurtotic, each were within acceptable parameters. Curren [175] suggests that univariate skewness >2 and kurtosis >7

present significant problems for maximum likelihood estimation [175]. In our sample univariate skewness ranged from -1.328 to 0.108, with a mean skewness of 0.192, while univariate kurtosis values range from -0.747 to 0.081, with a mean kurtosis of 0.246.

An important assumption is that data are *multivariate normal*, with Bentler [177] suggesting that values equal to or greater than 5 represent departure from multivariate normality [177]. The critical value of 3.375 fell within acceptable limits. Awang (2006) suggests that AMOS is robust to skewness and suggests that critical region (CR) values not exceeding 8 are acceptable, while critical region (CR) values not exceeding 8 are acceptable. Data exhibited critical region values for skewness ranging from -5.8 to 2.93, while critical region values for kurtosis ranged from -2.107 to 1.722, all within the parameters described, providing further evidence of the acceptability of the data for ML estimation.

The adequacy of models can be assessed in many ways and researchers typically use multiple criteria for goodness of fit [178]. The Chi Square statistic is used as a measure of absolute fit and assumes the null hypothesis, that there is no difference between the observed and expected results. A significant result suggests a difference between observed and expected values, or in the case of CFA the difference between the hypothesised model and the data. A  $\chi$ 2 statistic of less than three is conventionally looked to be an indicator of acceptable fit but only where the statistic is also non-significant. While we obtained a non-significant value (p=.105), the  $\chi$ 2 statistic itself was above 3.0 (chi sq=103.88) and may have been the result of skewed data and/or kurtosis [175]. There is some debate about the use of  $\chi$ 2 as an indicator of model fit and as a consequence there has been a shift from the use of chi square as a measure of 'absolute fit' to 'close fit' and the use of multiple indices to assess model adequacy.

Additionally, questions remain as to the utility and/or applicability of  $\chi^2$  as an indicator of model fit and that that any derived model should be interpreted with reference to other indices. Based on these arguments, rather than relying solely on  $\chi^2$  as an indicator of model fit, other indices of fit were employed to assess model adequacy (see below). The reporting of multiple fit indices is common practice and is recommended when assessing model fit to support the reliability of the findings [164, 174, 178-181].

We included the following indices: Root Mean Square Error of Approximation (RMSEA), p of Close fit (PCLOSE), Comparative Fit Index (CFI) and Tucker-Lewis

Index (TLI). The fit indices RMSEA, TLI and CFI are sensitive to model misspecifications and do not depend on sample size as strongly as  $\chi 2$ . RMSEA is regarded as one of the most informative fit indices [181], while CFI is one of the most popular fit indices because it is least affected by sample size. Results for each of these measures are presented in Chapter 5.

# **Final survey**

During the survey development process several items were eliminated from the preliminary survey. Table 3 - 5 presents the results of the above process. As can be seen, two items were removed at the pilot stage, two from the test-retest stage and five from the CFA stage.

# Table 3 - 5: Final survey indicating items eliminated at each stage of the survey development process

Legend:	eliminated at pilot stage
	eliminated at test-retest stage
	eliminated at CFA stage

	Stro Disa	ongly agree			Stron Agree	gly e
1. Much can be done to improve the quality of life for people with dementia.	1	2	3	4	5	
2. I prefer to have nothing to do with the care of dementia patients.	1	2	3	<mark>4</mark>	5	
3. Managing dementia is more often frustrating than rewarding.	1	2	3	4	5	
4. The early detection of dementia benefits the patient.	1	2	3	4	5	
5. It is important for relative/family carers of people with dementia to seek external support (e.g. counselling/support groups).	1	2	3	4	5	
<ol><li>Relatives/family carers of patients with dementia should be encouraged to contact Alzheimer's Australia.</li></ol>	1	2	3	4	5	
<ol><li>GPs are in the best position to help relatives/carers with organising care for someone with dementia.</li></ol>	1	2	3	4	5	
8. I fear communicating a diagnosis of dementia will damage the doctor patient relationship.	1	2	3	4	5	
9. Guidelines for the management of dementia would greatly assist in providing care.	1	2	3	4	5	
10. I prefer treating patients with other chronic diseases such as diabetes mellitus or hypertension.	1	2	3	4	5	
11. The term 'dementia' should be avoided when discussing a diagnosis with a carer/family member as it is likely to cause emotional distress.	1	2	3	4	5	
12. Patients with dementia should be informed early so they can plan for the future.	1	2	3	4	5	
<ol> <li>It is important to inform the person with dementia of the terminal course of the condition.</li> </ol>	1	2	3	<mark>4</mark>	5	
14. It is important to inform the relatives/family carers of the person with dementia of the terminal course of the condition.	1	2	3	4	5	
15. I feel frustrated because I do not know how to effectively treat people with dementia.	1	2	3	4	5	
16. Dementia is better treated by specialist physicians.	1	2	3	4	5	
17. I feel confident in my ability to discuss legal issues associated with a diagnosis of dementia.	1	2	3	4	5	
18. I feel confident in my ability to diagnose dementia.	1	2	3	4	5	

	Stro Disa	ongly agree			Strongly Agree
19. I feel confident in my ability to communicate a diagnosis of dementia to a patient	1	2	3	<mark>4</mark>	<mark>5</mark>
20. I feel confident in my ability to provide appropriate medical care for a person with dementia.	1	2	3	4	5
21. I feel confident in my ability to provide advice about managing dementia related symptoms.	1	2	3	4	5
22. I feel confident in my ability to provide advice about managing risky behaviours associated with dementia (e.g. driving, wandering)	1	2	<mark>3</mark>	<mark>4</mark>	5
23. I feel confident in my knowledge of local resources to assist families/carers caring for a person with dementia.	1	2	3	4	5
24. A geriatrician review is essential in any definitive diagnosis of dementia.	1	2	3	<mark>4</mark>	5

## Comparative analysis

Factor scores generated from the CFA were used to compute standardised summary scores for each subscale and a total score. These scores were used to measure differences between different GPRs and GPs based on experience and exposure to dementia. t-tests for independent samples were employed to establish potential differences between groups for total and subscale scores. Cronbach's alpha was calculated to assess the internal consistency of each of the subscales as well as total scores.

Table 3 - 6: The final General Practitioner Attitudes and Confidence Towards Dementia Survey

General Practitioner Attitudes and Confidence Towards Dementia Survey								
Please read the following statements carefully. Once you have read each statement, please								
circle the number on the scale that corresponds with your	answe	er betw	een 1 a	and 5, v	vhere 1			
is 'strongly disagree' 3 is 'neither agree nor disagree' and 5 is 'strongly agree'.								
	Stro	ngly		St	trongly			
	Disa	gree		Agree				
1. Much can be done to improve the quality of life for	1	2	3	4	5			
people with dementia.								
2. Managing dementia is more often frustrating than	1	2	3	4	5			
rewarding.								
3. The early detection of dementia benefits the patient.	1	2	3	4	5			
4. It is important for relative/family carers of people with	1	2	3	4	5			
dementia to seek external support (e.g. counselling/support								
groups).								
5. Relatives/family carers of patients with dementia should	1	2	3	4	5			
be encouraged to contact Alzheimer's Australia.								
6. GPs are in the best position to help relatives/carers with	1	2	3	4	5			
organising care for someone with dementia.								

#### General Practitioner Attitudes and Confidence Towards Dementia Survey

Please read the following statements carefully. Once you have read each statement, please circle the number on the scale that corresponds with your answer between 1 and 5, where 1 is 'strongly disagree' 3 is 'neither agree nor disagree' and 5 is 'strongly agree'.

	Strongly			St	rongly	
	Disagree			Agree		
7. I fear communicating a diagnosis of dementia will	1	2	3	4	5	
damage the doctor patient relationship.						
8. I prefer treating patients with other chronic diseases	1	2	3	4	5	
such as diabetes mellitus or hypertension.						
9. Patients with dementia should be informed early so they	1	2	3	4	5	
can plan for the future.						
10. I feel frustrated because I do not know how to	1	2	3	4	5	
effectively treat people with dementia.						
11. I feel confident in my ability to discuss legal issues	1	2	3	4	5	
associated with a diagnosis of dementia.						
12. I feel confident in my ability to diagnose dementia.	1	2	3	4	5	
13. I feel confident in my ability to provide appropriate	1	2	3	4	5	
medical care for a person with dementia.						
14. I feel confident in my ability to provide advice about	1	2	3	4	5	
managing dementia related symptoms.						
15. I feel confident in my knowledge of local resources to	1	2	3	4	5	
assist families/carers caring for a person with dementia.						

# **Survey application**

#### The Diagnosing Dementia Workshop

In Australia GPRs are required to engage in a learning program consisting of several learning units conducted by regional training providers in each state. "The Recognising, Diagnosing and Managing Dementia in General Practice" workshop was developed by the Wicking Dementia Research and Education Centre as a response to the expressed absence of appropriate dementia related content in GPR training programs. The program has been operational since 2011. The workshop was utilised as a learning unit for GPRs' training by a range of regional training providers, with a modified version (see Table 3 - 6) employed to support the professional development of GP Supervisors associated with the respective providers.

There are four key objectives of the workshop:

- 1. increase recognition and awareness;
- 2. improve attitudes towards diagnosis and treatment;
- 3. improve diagnosis and management skills;

4. increase capabilities and confidence.

The registrars' workshop consists of two 1.5-hour face to face presentations delivered by medical educators focusing on (a) recognising and diagnosing dementia and (b) managing dementia in general practice. The supervisors' workshop is a modified version of the registrars' workshop and seeks to support supervisors to teach registrars the diagnosis and management content provided in the registrar program (see Table 3 - 7).

The shortened version for supervisors is in acknowledgement of the supervisors' experience as GPs. While the registrar workshop is compulsory, the supervisor workshop is voluntary. Face-to-face medical education programs where participants can engage with peers and experts remain the most popular educational formats for Australian GPs [182]. A combination of delivery methods are employed in the workshop including didactic methods, video, case studies, role play, group discussion, which have been shown to produce positive training outcomes [130].

Central to the education program is a strong focus on participant interaction and engagement with the material. It has been reported that educational interventions requiring active learning and participation contribute to improvements in detection of dementia in primary care. Group discussions and role plays are incorporated throughout the presentations while medical educators use examples from the case studies and professional experiences of diagnosing and treating people with dementia to reinforce learning. Case studies are provided via video of the three stages of dementia and disclosing a diagnosis of dementia.

The workshop emphasises the beneficial aspects of early diagnosis and patient engagement from a palliative or therapeutic perspective, rather than a purely biomedical approach to dementia.

Content	GPR	GPS Workshop	Delivery Method
	Workshop	2 hour	
	2 x 1.5 hour	session	
	sessions		
Defining dementia	✓	✓ (brief)	Presentation, Q and A
Types of dementia including	✓	×	Presentation
Alzheimer's, vascular, Lewy body			
Early warning signs	✓	$\checkmark$	Presentation, Q and A

Table 3 - 7: Development and content of the workshops for GPRs and GPSs

Content	GPR	GPS Workshop	Delivery Method
	Workshop	2 hour	
	2 x 1.5 hour	session	
	sessions		
Consequences of not diagnosing	$\checkmark$	$\checkmark$	Discussion
dementia			
Barriers to diagnosis	$\checkmark$	$\checkmark$	Discussion
Criteria for diagnosis of Alzheimer's	$\checkmark$	$\checkmark$	Presentation
and vascular dementia			
History taking for dementia	$\checkmark$	×	Presentation, Q and A
Examining for dementia	$\checkmark$	✓ (brief)	Presentation, Q and A
Tests to do prior to diagnosis	$\checkmark$	$\checkmark$	Presentation, Q and A
Stages of dementia	$\checkmark$	$\checkmark$	Video, interactive,
			case study
Giving the diagnosis	$\checkmark$	✓ (detail)	Demonstration, Video,
			discussion, case study,
			role play
Domains affected by dementia	$\checkmark$	✓ (brief)	Presentation
Dementia prevention and risk factors	✓	×	Presentation
Management of dementia at stage 1	$\checkmark$	✓ (brief)	Presentation,
			discussion
Medications for dementia	$\checkmark$	$\checkmark$	Presentation
Driving with dementia	$\checkmark$	×	Presentation,
			discussion
Services for the patient and their	$\checkmark$	×	Presentation
family			
Management of dementia at stage 2	$\checkmark$	✓ (brief)	Presentation, Q and A
Carers as patients	$\checkmark$	$\checkmark$	Discussion
Management of dementia at stage 3	$\checkmark$	✓ (brief)	Presentation, Q and A
Dementia in the indigenous	$\checkmark$	×	Presentation
population			
Referrals	✓	×	Presentation
Resources	✓	<ul> <li>✓</li> </ul>	Online and hard copy

# Evaluation of the education program

The final validated GPACS-D was used to measure the impact of the diagnosing dementia workshop on each of the participant groups at both baseline and after the workshop. Additionally, comparisons were made to establish the impact based on group membership as well as differences between pre and post-test scores. Finally, the effect size of any difference was also calculated to gauge the impact of the workshop on each group.

# Participants, sampling, and recruitment

GPs were recruited from dementia education workshops conducted in four Australian States between 2014 and 2017 (see Chapter 6 for further detail). As

described above, the Dementia Education Workshop, conducted by regional training authorities in each state of Australia, was designed to increase the awareness and knowledge base among GPs in order to improve early or timely diagnosis rates and the management of dementia throughout the dementia trajectory. While knowledge was assessed by a knowledge test (DKAS), the GPACS-D was utilised to assess whether the workshop also impacted on the attitudes and confidence of GPs.

#### Analysis

In order to assess the utility of the GPACS-D we required an appropriate test group to assess not only sensitivity to change as a result of an educational intervention but also sensitivity to group differences such as professional status, experience, and prior training in dementia. For example, it is important to determine that any differences observed are not the result of sampling error. To achieve this, I required a sufficient sample of GPs who were undertaking a dementia educational workshop to be confident that any results were an accurate portrayal of the population – that they were representative. The adequacy of the sample size was estimated using a confidence level of .95 and a confidence interval of 5, the results of which confirmed the adequacy of each of our samples of GPRs and GP Supervisors for analysis. Additionally, we compared our sample characteristics (age and gender) with samples of other studies to provide an indication of the extent to which our sample was representative of general practitioners in Australia (see Chapter 6 for further detail).

We were interested in the impact of the respective workshops on GPRs and GP Supervisors. The pretesting and pilot phase of the process was used to assess face validity, reliability, sensitivity to change and the development of a preliminary model, and CFA used to assess goodness of fit and construct and discriminant validity of the final model. Next, I wanted to see how the GPACS-D performed in a workshop setting. I wished to determine if the tool was sensitive to change resulting from an intervention in relation to each individual group as well as between groups, and where we might expect to see a difference (see Chapter 6).

We used a t-test for independent samples to establish differences between groups as well as a t-test for paired samples to test for differences between pre and posttest periods for both GPRs and GP Supervisors. An analysis of the statistical power of each of these tests resulted in a statistic > .80 for both groups indicating that there was better than an 80% chance that the tests would detect an effect if one genuinely existed [165]; that is the likelihood of making a type I error is low – that an effect is significant when it is not.

Cohen's *d* was calculated to measure the effect size of any observed difference between T1 and T2 scores for each group with d=0.2 equivalent to a 'small' effect size, 0.5 a 'medium' effect size and 0.8 a 'large' effect size [183]. Utilising these statistics provides us with a measure of any change for each group, differences between groups and the effect size of any difference observed.

# Conclusion

We undertook a thorough and detailed process to both develop and validate the GPACS-D. The aim was to develop a valid and reliable tool that could be used across multiple settings to compare more than one group and within a pre-test post-test scenario. Phase one involved the development of the preliminary survey, the assessment of face and content validity via focus groups and an expert panel. Reliability was assessed via test-retest sampling comprising GPs and medical students who had not received dementia training. Sensitivity to change and the development of the preliminary model was obtained from pilot data using principal component analysis. In stage two the preliminary model was used on a sample of GP registrars and GP Supervisors to test its applicability and utility.

# Chapter 4 – Development of the GPACS-D

**Publication 1:** Development and preliminary psychometric properties of the General Practitioner Attitudes and Confidence Scale (GPACS) for dementia

Mason, R.L., Annear, M.J., Lo, A., McInerney, F., Tierney, L.T. and Robinson, A.L., 2016. Development and preliminary psychometric properties of the General Practitioner Attitudes and Confidence Scale (GPACS–D) for dementia. *BMC family practice*, 17(1), p.105

## Precis

This chapter was published as an original research article in the peer-reviewed journal, BMC Family Practice in August 2016 and outlines the process undertaken to develop a survey to measure the impact of dementia educational interventions on the confidence and attitudes of general practitioners towards the diagnosis and management of people with dementia.

The final version of the completed manuscript is included here, with references listed at the end of this thesis.

# Abstract

**Background**: International evidence suggests that dementia is under-diagnosed in the community and that General Practitioners (GPs) are often reluctant to engage to their fullest capability with patients who exhibit cognitive symptoms. This is potentially reflected by a lack of knowledge about the syndrome. However, it is also recognised that attitudes and confidence are important in relation to how and to what extent GP approach people with dementia. This research sought to develop a reliable and valid measure of GPs' attitudes and confidence towards dementia.

**Method**: The General Practitioner Attitudes and Confidence Scale (GPACS-D) was developed via a four-stage process, including initial content development, pretesting, pilot testing and psychometric evaluation, including Principal Component Analysis (PCA). Participants were recruited for pre-testing (n = 12), test-retest (n = 55), and dementia workshop pre- and post-education evaluation (n = 215).

**Results**: The process of scale development and psychometric evaluation resulted in a 20-item measure of GP attitudes and confidence towards dementia, with 4 items removed due to poor reliability, low sensitivity, or lack of model fit. Among 55 respondents who completed the scale on two occasions with no intervening education, Kappa coefficient scores ranged from fair (n = 2; candidates for removal), moderate (n = 5), substantial (n = 15), and almost perfect (n = 2). A test of the sensitivity of items to change following dementia education among 215 GPs indicated that, with the exception of one item, all scale responses exhibited significant differences between pre- and post-workshop scores, indicating acceptable sensitivity. With one further item removed due to a low communality score, the final PCA undertaken with the remaining 20 items support a fourcomponent solution, which accounted for 51.9% of the total variance. The internal consistency of the 20-item GPACS-D indicated a high level of overall reliability without redundancy (Cronbach's  $\alpha$ =.81).

**Conclusion**: The GPACS-D provides a reliable and preliminarily valid measure of GP attitudes and confidence towards dementia. The scale provides useful information for medical educators and researchers who are interested in evaluating and intervening in GP perceptions of the syndrome and their capacity to provide effective care.

*Keywords*: attitudes, confidence, dementia education, general practitioner, scale psychometrics.

#### Background

Dementia is under-diagnosed in Australia and comparably developed countries. Many older people with this syndrome have not received a formal diagnosis from a health practitioner [1]. It is widely acknowledged that general practitioners (GPs) are pivotal in facilitating early diagnosis of dementia and that their attitudes and confidence towards identification, treatment, and management of the syndrome play a key role in influencing dementia diagnosis and care [2]. Reported reluctance among some GPs to identify dementia and to make a formal diagnosis or refer to an appropriately qualified medical specialist [3], may reflect their negative attitudes towards the syndrome [4], as well as a lack of confidence in their ability to diagnose suspected dementia [5, 6].

Attitudes towards dementia have been reported as key determinants of physician engagement with a possible presentation of dementia [7]. For example, Cahill et al [8, p665] report that "therapeutic nihilism" (the belief that there is no treatment

or cure for dementia) means that GPs who hold this perception see no value or advantage to early diagnosis. Research underpinned by social psychological theories has focused particularly on how attitudes are formed and maintained and how they impact on behavioural intention, decisions to act, or actual clinical or health behaviours [9]. Whether an attitude is favourable or unfavourable has been reported to influence the type of response to the object of that attitude [9] – such as dementia. Boise et al [7] found that among physicians, attitude towards dementia is a key determinant of whether or not they conduct a detailed assessment of the patient.

Similarly, social psychological theories [10, 11] suggest that an association exists between confidence and behaviour within health care and other settings [12]. An individual's behaviour is influenced by confidence in their ability to perform a particular set of actions or procedures. Bandura [11] refers to this as *self-efficacy*, while Ajzen [13] describes it as *perceived behavioural control*. Both terms are concerned with an individuals' perceived ability to perform a particular behaviour and the impact of this perception on their intentions to act or actual practice [10]. Research suggests that levels of confidence in one's ability to diagnose, treat, or manage dementia may be correlated with the quality of care received [14]. The above theoretical framework is relevant to this study as it is estimated that one third of GPs lack confidence in their diagnostic skills, while two thirds lack confidence in the management of behaviours associated with dementia [8].

A GP's response to a patient presenting with possible dementia is, therefore, not only influenced by their attitudes towards the syndrome but also by perceptions of their ability to perform a diagnosis and assist in the management of the syndrome. Research indicates that there is a positive correlation between selfestimated confidence and general attitudes towards caring for people with dementia. For example, Kaduszkiewicz et al [15] found that physicians with a negative attitude towards caring for patients with dementia reported a lack of belief in their ability to improve the patients' quality of life, while the opposite was true for those with a positive attitude [16]. Such findings provide support for the conceptualisation of attitudes and confidence as co-related influences on how a GP may be expected to engage with a person with dementia. Few studies have explored the co-related concepts of attitudes and confidence using a valid and reliable instrument. In relation to dementia education programs, which attempt to overcome attitudinal and confidence deficits by increasing clinician knowledge, no attempt to measure changes prior to and after an intervention have been undertaken. As reported by Liu et al. [17, p14], "There are no studies on how

dementia training affects the confidence and attitudes of physicians". The aim of the current research, therefore, was to develop a reliable and valid scale that accurately measures GP attitudes and confidence in relation to the diagnosis, treatment, and management of dementia at baseline and after a targeted educational intervention.

#### Method

The GP Attitudes and Confidence Scale (GPACS-D) was developed via a four-stage process, including initial content development, pretesting, pilot testing and psychometric evaluation. This process is consistent with published scale development procedures [18]. Throughout the development of the scale, refinement and item reduction was informed by expert feedback and an analysis of pilot results.

#### Participants, sampling, and recruitment

During the initial scale development, two cohorts of purposively selected expert participants were recruited to inform item content and construction. Twelve GPs comprised a *focus group*, while eight health professionals and academics comprised the project team and included GPs, medical educators, nurse academics, and social scientists. Both groups were recruited to pre-test the survey and provide critical feedback to establish face and content validity. These groups were selected due to their knowledge and experience working with people who have dementia, educating health professionals about dementia, and/or their expertise in scale development. The focus group and research team participants were recruited via email invitation through local training and organisational networks.

Following initial development of the scale, a convenience sample of 55 respondents comprising 28 final year medical students and 17 GPs, was recruited by letter of invitation from a School of Medicine at an Australian University to take part in a test-retest procedure to confirm the reliability of survey items. In the subsequent pilot study, 215 GPs participated in a dementia-related workshop, conducted throughout Australia between January and September 2015, and completed the GPACS-D before and after the education. The face-to-face workshop, run over 3 hours, involved a combination of teaching methods including lectures, video case studies, group discussions, and role playing. All workshop participants were invited to complete the GPACS-D before and after the education. Participants were provided with information about the research, and

completion of the survey implied consent. The University of Tasmania Human Research Ethics Committee reviewed and approved this study (Reference Number: H0012046).

#### Development procedures and psychometric evaluation

#### Stage 1: Content development

Scale content was developed from information obtained during a scoping literature review from which a pool of 24 potential scale items was compiled [2, 6, 15, 16, 19-21]. Items were sent to the project team for critical review and refinement (RM, AL, AR, MA, FM), focusing on question construction, interpretability, and relevance. Editing and refinement of survey items was iterative and achieved by sending successive versions of the draft instrument to each member of the project team for feedback. The preliminary version of the GPACS-D comprised 24 declarative statements and employed a 5-point, Likert-type scale with responses varying from *strongly disagree* to *strongly agree*, which measured respondent sentiment in relation to the topic areas of, early diagnosis, the efficacy of treatment, resources, and support, as well as perceived confidence in relation to the diagnosis, treatment, and management of dementia.

#### Stage 2: Pretesting

Pretesting was conducted to establish the face and content validity of the tool and included the use of the focus group (referred to above) of 12 GPs, who completed the draft survey and commented on item construction, content appropriateness, relevance, and breadth of scope. Feedback provided by the focus group was collated under each survey item and presented to the expert panel for critical review, from which the 24-item scale was developed.

#### Stage 3: Pilot administration

In order to evaluate the test-retest reliability of the GPACS-D, the tool was administered to 55 respondents who had medical training (38 final year medical students and 17 GPs), with two weeks elapsing between the first and second administration, and no intervening education. The survey was also administered at a series of dementia education workshops to determine the internal consistency and construct validity of the measure. In total, 215 GPs completed the survey prior to and directly after the workshop.

#### Stage 4: Evaluation of psychometric properties and instrument refinement

A process of item evaluation and reduction was undertaken, through an examination of pilot responses to ensure that only the most reliable and valid items were included in the scale. Following the initial removal of items that exhibited poor reliability and construct validity, Principal Component Analysis (PCA) was performed to further refine the scale, determine preliminary factorial validity, and identify potential subscales within the measure.

#### Analysis

All data analyses were conducted using Statistical Package for the Social Sciences (SPSS) (Version 20) [22]. Considering the level of measurement (ordinal), nonparametric measures of intra-rater reliability were an appropriate analytic approach. A weighted Kappa (k) coefficient was used to provide a measure of testretest reliability. Weighted Kappa is appropriate for use with ordinal data and is equivalent to the intra-class correlation coefficient [23]. The following have been identified as standards for strength of agreement for Kappa coefficients: 0 = 'poor'; .01-.20 = 'slight'; .21-.40 = 'fair'; .41 to .60 = 'moderate'; .61-.80 = 'substantial'; .81-1.00 = 'almost perfect' [24, 25]. A Kappa coefficient above .40 was selected as the cut-off for item selection as suggested by Fleiss et al. [26]. Expected and observed agreement levels are also reported. Items with a Kappa coefficient above .40 and an observed agreement score of 90% or better were deemed reliable [27] and retained, while items scoring below any of these criteria were excluded. A Wilcoxon signed ranks test for paired samples was undertaken to identify potentially significant differences between survey item scores obtained from the pilot study to assess each item's sensitivity to change (a measure of construct validity) following educational intervention (dementia workshop). Items exhibiting a non-significant difference between pre- and post-education administration were identified as candidates for elimination. One item, I prefer to have nothing to do with the care of dementia patients was eliminated as a result. An exploratory analysis employing PCA was undertaken (with Varimax rotation) to identify any patterns among variables. Any items exhibiting poor fit were eliminated at this stage of the analysis with the PCA being re-run to produce a final factor solution. Finally, tests of internal consistency utilising a Cronbach's alpha ( $\alpha$ ) value was calculated for the overall scale and each of the potential sub scales indicated by the PCA.

## Results

In total, 270 GPs participated in pilot testing the GPACS-D measure, including 55 respondents in a test-retest administration and 215 who completed the scale before and after a dementia workshop. The workshop sample comprised 3% medical educators (n = 8), 65% GP Registrars (n = 139), 32% GPs (n = 68). The mean age of respondents was 39.27 (Standard Deviation (SD) = 11.4), 63% were born in Australia (n = 132), and 66% were female (n = 92). A 100% response rate for the test-retest phase and a 93% response rate for the pilot testing workshop were achieved. The very high level of participation among the GP cohort undertaking the workshop suggests that the samples are likely to be representative of Australian GPs who are undergoing specialised GP post-graduate training.

## Test-retest reliability

Among 55 respondents to the GPACS-D who completed the scale on two occasions with no intervening education, Kappa coefficient scores ranged from 'fair' to 'almost perfect' reliability [24], with 0 items rated as 'poor', two items rated 'fair', 5 items rated 'moderate', 15 items rated 'substantial', and two items rated 'almost perfect'. Additionally, observed agreement between time one and time two scores was significantly higher than expected agreement, with over 90% agreement scored on all items [27]. These results indicate good test-retest reliability with the exception of two *items: I feel confident in my ability to communicate a diagnosis of dementia to a patient*, and *I feel confident in my ability to provide advice about managing risky behaviours (e.g. driving, wandering)*, where coefficient scores were below the inclusion criteria of .40 cited above (see Table 4 - 1). These two items were eliminated due to poor reliability.

Su	rvey Item	Kappa*	SE Kappa	CI 95%	Expected Agreeme nt (%)	Observed Agreement (%)	'p'**
1.	Much can be done to improve the quality of life for people with dementia	.707	.140	.430980	84.8	95.6	.0000
2.	I prefer to have nothing to do with the care of dementia patients	.781	.138	.511-1.00	74.9	94.5	.0000

Table 4 - 1: Test-retest result.
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Survey Item		Kappa*	SE	CI	Expected Agreeme	Observed Agreement	'p'**
			карра	95%	nt (%)	(%)	
3.	Managing dementia is more often frustrating than rewarding	.577	.138	.270847	90.55	96.0	.0000
4.	The early detection of dementia benefits the patient	.722	.140	.450994	88.80	96.9	.0000
5.	It is important for relative/family carers of people with dementia to seek external support	.558	.141	.282833	90.96	96.0	.0000
6.	Relatives/family carers of patients with dementia should be encouraged to contact Alzheimer's Australia	.544	.127	.306792	90.25	95.6	.0000
7.	GPs are in the best position to help relatives/carers with organising care for someone with dementia	.639	.140	.365913	86.46	95.1	.0002
8.	I fear communicating a diagnosis of dementia will damage the doctor patient relationship	.511	.138	.241781	89.56	94.9	.0001
9.	Guidelines for the management of dementia would greatly assist in providing care	.686	.134	.424948	92.83	97.8	.0000
10	I prefer treating patients with other chronic diseases such as diabetes mellitus or hypertension	.764	.141	.487-1.00	88.37	97.3	.0000
11.	The term 'dementia' should be avoided when discussing a diagnosis with a carer/family member as it is likely to cause emotional distress	.704	.137	.436972	92.40	97.8	.0000
12.	Patients with dementia should be informed early so they can plan for the future	.685	.138	.415995	94.44	98.3	.0000
13	It is important to inform the person with dementia of the terminal course of the condition	.877	.140	.603-1.00	87.85	98.5	.0000

Survey Item	Kappa*	SE Kappa	CI 95%	Expected Agreeme	Observed Agreement	'p'**
14. It is important to inform the relatives/family carers of the person with dementia of the terminal course of the condition	.884	.139	.612995	90.33	98.9	.0000
<ol> <li>I feel frustrated because         <ul> <li>I do not know how to             effectively treat people             with dementia</li> </ul> </li> </ol>	.723	.139	.451995	79.96	94.4	.0000
<ol> <li>Dementia is better treated by specialist physicians</li> </ol>	.669	.141	.364945	89.07	96.4	.0000
<ol> <li>I feel confident in my ability to discuss legal issues associated with a diagnosis of dementia</li> </ol>	.640	.139	.368912	87.84	95.6	.0000
<ol> <li>I feel confident in my ability to diagnose dementia</li> </ol>	.628	.139	.356900	90.61	96.5	.0000
<ol> <li>I feel confident in my ability to communicate a diagnosis of dementia to a patient</li> </ol>	.374	.140	.098650	93.42	95.9	.0040
20. I feel confident in my ability to provide appropriate medical care for a person with dementia	.632	.141	.403908	91.16	96.8	.0000
<ol> <li>I feel confident in my ability to provide advice about managing dementia related symptoms</li> </ol>	.679	.141	.403995	83.41	94.7	.0000
<ol> <li>I feel confident in my ability to provide advice about managing risky behaviours associated with dementia</li> </ol>	.388	.138	.116660	90.20	94.0	.0026
23. I feel confident in my knowledge of local resources to assist families/carers caring for a person with dementia	.517	.140	.243791	83.44	92.0	.0001

Survey Item	Kappa*	SE Kappa	CI 95%	Expected Agreeme nt (%)	Observed Agreement (%)	'p'**
<ul> <li>24. A geriatrician review is essential in any definitive diagnosis of dementia</li> </ul>	.694	.141	.418970	88.16	96.4	.0000

SE: Standard Error

\* Weighted Kappa (quadratic)

\*\* Significant at .001 level

#### Construct validity: sensitivity to change

Two hundred and fifteen participants completed the GPACS-D before and after dementia education. With the exception of one item, *I prefer to have nothing to do with the care of dementia patients*, all responses to scale statements exhibited significant differences between pre- and post-workshop scores, indicating both acceptable and hypothesized sensitivity to change (see Table 4 - 2). The item that showed no significant change following dementia education was eliminated.

Survey Item	Pre- Workshop Mean (n=215)	Post- Workshop Mean (n=215)	ʻz'	'p'
<ol> <li>Much can be done to improve the quality of life for people with dementia</li> </ol>	4.19	4.55	5.769	.000
<ol><li>I prefer to have nothing to do with the care of dementia patients</li></ol>	1.73	1.64	.754	.451
<ol> <li>Managing dementia is more often frustrating than rewarding</li> </ol>	2.82	2.37	6.264	.000
<ol> <li>The early detection of dementia benefits the patient</li> </ol>	4.18	4.59	6.313	.000
<ol> <li>It is important for relative/family carers of people with dementia to seek external support</li> </ol>	4.51	4.73	4.582	.000
<ol> <li>Relatives/family carers of patients with dementia should be encouraged to contact Alzheimer's Australia</li> </ol>	4.37	4.61	5.256	.000
<ol> <li>GPs are in the best position to help relatives/carers with organising care for someone with dementia</li> </ol>	3.99	4.37	6.391	.000
8. I fear communicating a diagnosis of dementia will damage the doctor patient relationship	1.95	1.64	4.331	.000
<ol> <li>Guidelines for the management of dementia would greatly assist in providing care</li> </ol>	4.23	4.41	3.752	.002

Table 4 - 2: Pilot results for individual survey items – pre and post workshop

Survey Item	Pre- Workshop Mean (n=215)	Post- Workshop Mean (n=215)	'z'	'p'
<ol> <li>I prefer treating patients with other chronic diseases such as diabetes mellitus or hypertension</li> </ol>	3.06	2.63	6.016	.000
11. The term 'dementia' should be avoided when discussing a diagnosis with a carer/family member as it is likely to cause emotional distress	1.89	1.46	5.673	.000
12. Patients with dementia should be informed early so they can plan for the future	4.29	4.70	6.655	.000
<ol> <li>It is important to inform the person with dementia of the terminal course of the condition</li> </ol>	3.64	4.06	8.365	.000
14. It is important to inform the relatives/family carers of the person with dementia of the terminal course of the condition	4.02	4.65	9.055	.000
15. I feel frustrated because I do not know how to effectively treat people with dementia	3.35	2.26	9.860	.000
<ol> <li>Dementia is better treated by specialist physicians</li> </ol>	2.75	2.14	7.352	.000
<ol> <li>I feel confident in my ability to discuss legal issues associated with a diagnosis of dementia</li> </ol>	2.54	3.39	8.671	.000
<ol> <li>I feel confident in my ability to diagnose dementia</li> </ol>	2.85	3.94	10.770	.000
19. I feel confident in my ability to communicate a diagnosis of dementia to a patient	3.18	4.06	9.883	.000
20. I feel confident in my ability to provide appropriate medical care for a person with dementia	3.09	3.95	10.061	.000
21. I feel confident in my ability to provide advice about managing dementia related symptoms	2.89	3.86	10.398	.000
22. I feel confident in my ability to provide advice about managing risky behaviours associated with dementia	2.85	3.68	9.599	.000
23. I feel confident in my knowledge of local resources to assist families/carers caring for a person with dementia	2.63	3.55	9.828	.000
24. A geriatrician review is essential in any definitive diagnosis of dementia	3.37	2.23	10.306	.000

## Principal component analysis

A total of 21 items were retained for the PCA. Preliminary analysis confirmed the factorability of the data set (KMO = .811, Bartlett's test of Sphericity p < .001). One item, a geriatrician review is essential in any definitive diagnosis of dementia,

exhibited a low communality score and was removed from the analysis, indicating that the item did not fit well in the solution. The final PCA, undertaken with the remaining 20 items, identified the presence of four components with eigenvalues exceeding 1.0, explaining 23.1%, 14.6%, 7.76% and 7.47% of the variance respectively, with the four-factor solution accounting for 51.9% of the total variance. Varimax rotation indicated that 5 to 8 variables loaded significantly on each component. Loadings of <.30 was employed as the cut-off.

Results indicate the presence of four potential sub scales within the measure, which have acceptable factorial validity. Low to moderate correlation between components (.01 to .28) supports the potential presence of distinct subscales. The four identified components were examined by the project team and conceived as: a) *Confidence in clinical abilities*; b) *Support for quality of life and care*; c) *Fears and frustrations*; and d) *Communication about dementia progression*. The loadings and interpretation of components indicate that the survey has acceptable preliminary factorial validity.

#### Internal consistency

The internal consistency of the 20 item GPACS-D was obtained using Cronbach's alpha which indicated a high level of overall reliability without item redundancy (Cronbach's  $\alpha$ =.81; see Table 4 - 3). Internal consistency of each of the hypothesised subscales ranged from .62 to .89, which is generally indicative of moderate to good internal consistency [28].

	Survey Item	Confidence in clinical abilities	Support for quality of life and care	Communication about dementia progression	Fears and frustrations
1.	Much can be done to improve				
	the quality of life for people with		.622		
	dementia				
2.	Managing dementia is more		227		166
	often frustrating than rewarding		.527		.400
3.	The early detection of dementia		560		
	benefits the patient		.500		
4.	It is important for relative/family				
	carers of people with dementia		.522		
	to seek external support				

	Survey Item	Confidence in clinical abilities	Support for quality of life and care	Communication about dementia progression	Fears and frustrations
5.	Relatives/family carers of				
	patients with dementia should		704		
	be encouraged to contact		.704		
	Alzheimer's Australia				
6.	GPs are in the best position to				
	help relatives/carers with		.570		
	organising care for someone with				
	dementia				
7.	I fear communicating a diagnosis				
	of dementia will damage the				.782
	doctor patient relationship				
8.	Guidelines for the management				
	of dementia would greatly assist	.304	.451		
	in providing care				
9.	I prefer treating patients with				
	other chronic diseases such as	.310			.426
	diabetes mellitus or				
10	nypertension				
10.	The term "dementia" should be				
	avoided when discussing a				745
	mamber as it is likely to says				.745
	ametional distrass				
11	Patients with domentia should				
11.	he informed early so they can		457	516	
	plan for the future		.437	.510	
12	It is important to inform the				
12.	person with dementia of the			849	
	terminal course of the condition			1045	
13.	It is important to inform the				
	relatives/family carers of the				
	person with dementia of the			.867	
	terminal course of the condition				
14.	I feel frustrated because I do not				
	know how to effectively treat	.562		.384	.381
	people with dementia				
15.	Dementia is better treated by				
	specialist physicians	.612			
16.	I feel confident in my ability to				
	discuss legal issues associated	.755			
	with a diagnosis of dementia				
17.	I feel confident in my ability to	776			
L	diagnose dementia	.//0			
18.	I feel confident in my ability to				
	provide appropriate medical care	.807			
	for a person with dementia				

Survey Item	Confidence in clinical abilities	Support for quality of life and care	Communication about dementia progression	Fears and frustrations
19. I feel confident in my ability to				
provide advice about managing	.826			
dementia related symptoms				
20. I feel confident in my knowledge				
of local resources to assist	713			
families/carers caring for a	./15			
person with dementia				
Eigen values for component	4.62	2.92	1.50	1.56
Variance explained	23.1	14.6	7.47	7.76
Cronbach's alpha	.886	.616	.741	.633

Extraction Method: Principal component analysis

Rotation Method: Varimax with Kaiser normalisation

Bold text indicates those items defining each of the identified factors.

## Discussion

Findings from this study demonstrate sound psychometric properties of the 20item GPACS-D. During the analysis, four items were removed from the original 24item preliminary version based on the exclusion criteria (poor test-retest reliability, non-significant sensitivity to change, and low communality score in the PCA). Test-retest reliability was confirmed among individuals who had not undertaken specific dementia training or education. Face and content validity were achieved through a scoping review of contemporary literature, focus group discussions with GPs, and pretesting with an expert panel. Construct validity (sensitivity to change) was confirmed through analysis of the results of GPACS-D administration before and after a dementia education workshop. Preliminary factorial validity was supported by the interpretability of PCA results, which indicated that the GPACS-D fits an interpretable four-factor solution. Specific components of the scale include a) confidence in clinical abilities, b) support for quality of life and care, c) communication about dementia progression, and d) fears and frustrations. GPACS-D total and factor scores display moderate to good internal consistency suggesting they reflect both overarching and underlying constructs.

The GPACS-D is among the first scales to provide a theoretically informed measure of dementia-related attitudes and confidence that is suitable for administration with medically trained individuals in Australia. Previous studies have reported that attitudes towards particular health conditions and confidence in one's ability to diagnose, treat, and manage these are correlative with the resultant behaviours and practices of medical professionals [17]. Moreover, when negative attitudes and a lack of confidence has been reported in the literature, GP behaviours towards particular health conditions have been identified as less than optimal [16]. These results are consistent with social psychological theories associated with health and treatment behaviour [10]. These theoretical perspectives suggest that attitude affects the way in which an individual approaches the object of that attitude (in this instance, a patient with suspected dementia). Moreover, confidence (often defined as self-efficacy or perceived behavioural control) is considered vital in relation to the extent to which a GP engages a patient who may be presenting with symptoms of dementia. The GPACS-D provides a new mechanism to measure the attitudes and confidence levels of GPs at baseline as well as following dementia-specific educational interventions.

Counteracting ingrained attitudes associated with diagnosing and treating people with dementia [4] is a significant task for medical educators. The key to countering such attitudes and, therefore, improving recognition of dementia, is arguably targeted educational programs [3]. Targeted educational interventions aim to increase awareness and inform participants about a particular subject matter, in this case the diagnosis and management of dementia. Scales that accurately measure change in attitudes and confidence are fundamental because the manner in which dementia is approached and managed relies on far more than an individual's knowledge about the subject (although knowledge is conceptually related to both attitudes and confidence) [7]. Additionally, a scale that accurately measures changes in attitudes and confidence provides a basis from which to conduct research that aims to elucidate whether improving attitudes and confidence can affect positive change in the treating behaviour of medical practitioners.

#### Limitations

The GPACS-D has been developed with an Australian cohort of GPs and more work is required with an international cohort of medical professionals to validate the scale for a global population. There is also likely to be some variation in attitudes towards and confidence associated with dementia between medical professionals in more and less developed countries where levels of exposure to the syndrome vary based on prevalence. It may also be possible to develop a version of the GPACS-D that is valid and reliable when administered with a wider population of health professionals who routinely interact with people who have dementia (such as nurses and allied health professionals).

A confirmatory factor analysis (CFA) is required to validate the four hypothesised subscales that were identified via the PCA. While the four subscales appear consistent with the theory and literature, they cannot yet be considered valid submeasures. It is hypothesised that scoring of the GPACS-D will be most effective when summaries can be derived for the four subscales as these potentially measure distinct (though co-related) constructs related to attitudes and confidence.

## Conclusion

We have presented the results from the first phase in the development and testing of the GPACS-D. Phase one results suggest that a 20-item measure (four items removed based on exclusion criteria) is reliable and valid when administered to a sample of medically trained individuals. In its current format, the GPACS-D is suitable for administration as a measure of attitude and confidence change before and after targeted dementia education with analysis permissible at the item level. Further CFA is indicated with a larger, de novo population of medically trained individuals, in order to confirm the validity and utility of the measure with several subscales hypothesised. Theorised relationships between attitude, confidence, and behaviour identified by social psychologists suggest that improving GP knowledge through targeted education may affect clinical behaviour mediated by attitude and confidence. In this way, changes in confidence and attitude may be an indicator of intention to change one's behaviour and, thus, flag potential improvements in clinical care for people with dementia.

# Chapter 5 - Confirmation and validation of the GPACS-D

**Publication 2:** General practitioners' attitude and confidence scale for dementia (GPACS-D): confirmatory factor analysis and comparative subscale scores among GPs and supervisors

Mason, R., Doherty, K., Eccleston, C., Annear, M., Lo, A., Tierney, L., McInerney, F. and Robinson, A., 2019. General practitioners' attitude and confidence scale for dementia (GPACS-D): confirmatory factor analysis and comparative subscale scores among GPs and supervisors. *BMC family practice*, 20(1), pp.1-8.

# Precis

This chapter was published as an original research article in the peer-reviewed journal, BMC Family Practice in June 2019. The focus of the paper was to confirm the psychometric properties of the preliminary GPACS-D tool by assessing the extent to which the hypothesised model fit the data and the construct and discriminant validity of each of the hypothesised subscales contained within the tool.

The final version of the completed manuscript in included here, with references listed at the end of this thesis.

# Abstract

# Background

The attitude of General Practitioners (GPs) towards dementia and confidence in their clinical abilities impacts on diagnosis rates and management of the condition. The purpose of the present research is to refine and confirm the reliability and validity of the General Practitioner Attitudes and Confidence Scale for Dementia (GPACS-D) as a tool to measure confidence and attitude.

# Method

A sample of 194 GP volunteers attending dementia education workshops were recruited to complete the GPACS-D before and after the workshop. Volunteer respondents comprised both GP Registrars and GP Supervisors. Analyses included confirmatory factor analysis (CFA), measures of internal consistency, Pearson correlations, and a comparison of subscale scores between cohorts (T-Test for independent samples).

#### Results

Findings of the CFA support a 15-item, 3-factor model with four items removed due to poor performance and one item moved between factors. The resultant model exhibited good fit (x<sup>2</sup>=103.88; p=.105; RMSEA=.032; PCLOSE=.915; CFI=.967; TLI=960), with acceptable internal consistency. Subscales exhibited clear discriminant validity with no underlying relationships between subscales. Finally, total and subscale scores exhibited good discrimination between groups who would be expected to score differently based on experience and level of exposure to dementia.

#### Conclusion

The 15-item, 3-subscale GPACS-D is a reliable and valid measure of GP confidence and attitudes toward dementia. The subscales clearly distinguish between groups who might be expected to score differently from each other based on their training or professional experiences. The psychometric properties of the GPACS-D support its use as a research tool.

*Key Words:* attitudes, confidence, dementia education, general practitioner, scale validation.

#### Background

Timely and accurate diagnosis of dementia is widely acknowledged to be beneficial to health care providers, patients and their families through more effective management of symptoms and concerns, prompt care planning and a proactive approach to social support [14]. However, low rates of diagnosis persist, with a recent study determining that 59% of adults with probable dementia have either not been diagnosed or are unaware of their diagnosis [21]. This has been attributed to multiple factors involving the health care provider, the patient, their families and the health system [7]. For the family physician, their attitude toward dementia, including the potentially stigmatising impact of a dementia diagnosis and concerns about its benefits, together with difficulty in communicating effectively with patients and their families have been identified as important contributing factors to low diagnosis rates [7]. While GP attitudes toward caring for people with dementia have been shown to be positive [184], fear of misdiagnosis and lack of confidence in diagnostic and dementia management skills have been reported to be of particular concern in multiple studies with a lack of

effective education and training frequently cited as an underlying cause [25, 27, 30].

Intervention trials of dementia education and training programs often use rates of detection, and compliance with practice guidelines as key outcome measures [23, 130], however assessment of practitioner confidence and attitudes are equally important indicators of educational effectiveness [130]. Where this has been explored, dementia education can be shown to improve practice quality while having little positive impact on the knowledge or attitude to dementia of primary care providers [35]. Survey based measures have been used to establish attitudes and/or confidence levels of health practitioners toward dementia [30, 112], or in depth interviews used to explore attitudes and barriers to diagnosis [118]. O'Connor and McFadden [56] reported the development of the Dementia Attitudes Scale which has been used to explore attitudes to dementia in medical students and other groups of health care professionals, but this tool does not address issues associated with confidence which have particular relevance to general practice. Liu and co-workers (2013) used a postal questionnaire to compare attitudes to dementia of physicians who had or had not received dementia specific training. Using exploratory factor analysis (EFA) two factors were identified: confidence and negative views, which underpinned attitudes to dementia. Those who had received training were more confident and held less negative views, although the type of training received was not controlled in this study as it was self-reported [109].

Given that physicians report the need for better education about dementia as a step toward practice change and acknowledging the importance of confidence and attitude towards dementia in effecting change, evaluation of the effectiveness of educational interventions should include assessment of both confidence and attitude. In a recently published paper [185], the authors reported the development of the General Practitioner Attitudes and Confidence Scale for Dementia (GPACS-D). Informed by social psychological theories of health and practice behaviour [40], principal component analysis (PCA) resulted in four hypothesised subscales; *Confidence in Clinical Abilities; Attitude to Care; Attitude to Care; Attitude to Communication* and *Fears and Frustrations*. These subscales reflect an interrelationship between attitudes, confidence (self-efficacy or perceived behavioural control), intention and resultant behaviours [7, 109].

*Confidence in Clinical Abilities* subscale includes items addressing diagnostic and clinical abilities [184], management of symptoms associated with the syndrome

[109] and knowledge of external resources, including respite services [22, 25]. The *Attitude to Care* subscale focusses on attitudes to early diagnosis [7], the role of the GP in organising care, including external support [30], and the inclusion of both the patient and carer/s in the diagnosis and future management of dementia [112]. The *Fears and Frustrations* subscale reflects frustration with and/or avoidance of treating dementia, and includes difficulty in diagnosing dementia or the management of dementia related symptoms [27, 109] and a preference for treating other conditions. The *Attitude to Communication* subscale reflects perspectives on diagnosis disclosure to the patient so they can plan for the future [186], as well as informing patients and their families of the terminal nature of the condition [14]. The preliminary GPACS-D scale demonstrated sound psychometric properties, with each survey item exhibiting good test-retest reliability, sensitivity to change and good internal consistency [185].

The purpose of the present research is to confirm the reliability and validity of GPACS-D as a tool to measure GP attitudes and confidence towards dementia. The construct validity of the hypothesised GPACS-D subscales was established by undertaking confirmatory factor analysis (CFA) to evaluate the adequacy of the model resulting in a final model suitable for research application.

#### Method

#### Sample

Purposive sampling was employed to recruit GP supervisors and registrars (GPRs) participating in Recognising, Diagnosing and Managing Dementia in General Practice Workshops conducted in three Australian states: Tasmania, New South Wales and Queensland between June and December 2016. GPRs are medical graduates undertaking a vocational training program to specialise in general practice (Australian Government Department of Health 2017). GP supervisors are experienced GPs who have regular contact with registrars and oversee their patient care, provide support and feedback to facilitate learning (Australian Government Department of Health 2017). Volunteer participants were provided with information about the research prior to their participation in the workshop and invited to complete the survey. Sample size adequacy was determined according to criteria set out by Tabachnick et al (2001), where a subject to item ratio of 10:1 is desirable for CFA. Our data set comprised 194 cases and was therefore considered acceptable to draw inferences from the data [145]. Completion of the survey implied consent consistent with Australian National

Health and Medical Research Council guidelines. A University Human Research Ethics Committee reviewed and approved this study (Reference Number: H0012046).

#### Measure

The survey comprises 20 items designed to address GP attitudes towards (a) diagnosis and treatment, (b) confidence in clinical skills and (c) awareness of support networks for dementia. Survey items were measured via a 5-point Likert Scale (1=strongly disagree; 5 = strongly agree). Because no a priori assumptions were made about the relationship amongst the variables in the original survey, principal component analysis (PCA) was previously employed to reduce the set of observed variables to a smaller, more interpretable structure and to identify potential constructs for further examination and refinement [66], prior to further validation. The present study sought to confirm these constructs as valid, reliable, and independent subscales within the GPACS-D measure using CFA.

#### Data analysis

All analyses were undertaken using SPSS (Version 22) and Analysis of a Moment Structures (AMOS) (for structural equation modelling). Because estimation procedures are dependent upon the distribution of the data, an analysis of data properties was undertaken to establish the extent to which data were normally distributed. Data were highly skewed and kurtotic, however each were within acceptable parameters. Curren (1996) suggests that univariate skewness >2 and kurtosis >7 present significant problems for maximum likelihood estimation. In our sample univariate skewness ranged from -1.328 to 0.108, with a mean skewness of 0.192, while univariate kurtosis values range from -0.747 to 0.081, with a mean kurtosis of 0.246. While it is necessary to check for univariate normality it is not always a sufficient condition for multivariate normality.

An important assumption is that data are multivariate normal, with Bentler (2005) suggesting that values equal to or greater than 5 represent departure from multivariate normality [177]. Our Critical value of 3.375 falls within acceptable limits. Given this maximum likelihood estimation was considered appropriate for model development.

Confirmatory factor analysis (CFA) was undertaken to assess the quality of the hypothesised factor structure [144] previously identified via principal components analysis (PCA) [185]. CFA also sought to confirm the construct and discriminant validity of each of the subscales. Parameter estimates were examined to establish utility, while potential item misspecification was identified through an examination of the standardised residuals (values >1.96) and modification indices (values <.30) [163, 173].

Consistent with CFA reporting conventions, goodness of fit measures included Chi Square, Root Mean Square Error of Approximation (RMSEA; values < 0.06 are desirable); (PCLOSE; values >0.50 are desirable); Comparative Fit Index (CFI; values >0.95 are desirable) and Tucker-Lewis Index (TLI; values >.95 are desirable). The reporting of multiple fit indices is common practice and is recommended when assessing model fit to support the reliability of the findings [164, 174, 178-181].

## Comparative analysis

Factor scores generated from the CFA were used to compute standardised summary scores for each subscale and a total score. Because of reverse scoring a higher score for *Fears and Frustrations* indicate less frustration. These scores were used to measure differences between different cohorts based on experience and exposure to dementia. T-tests for independent samples were employed to establish potential differences between groups for total and subscale scores.

#### Results

A total of 194 respondents completed the survey with a response rate of 93%. The sample comprised 39% Supervisors (n=76) and 61% GP Registrars (n=118). The mean age of respondents was 37 years of age (SD = 8.70), 54% were female (n=93) and 38% were born in Australia (n=72). See Table 5 - 1 for full demographic information.

#### Table 5 - 1: Demographic information

	Sample Size (n=194)		
Mean age	37.2 (SD=8.70)		
Age range	25-66		

	Sample Size (n=194)
Male respondents	(n=85) 45.7%
Australian born	(n=72) 38%
Occupational groups:	
Registrar	(n=118) 61% <i>Male</i> (44%)
Supervisor	(n=76) 39% <i>Male</i> (56%)
Prior dementia education	(n=18) 9%
Family member with dementia	(n=68) 36.6%
Provided professional services for person with dementia	(n=162) 84%

#### Confirmatory factor analysis

The initial 20-item four factor model hypothesised by the PCA returned a significant Chi Square statistic ( $x^2$ =247.62; p=.000) indicating a lack of fit between the hypothesised model and the observed data. Post-hoc analyses were undertaken to refine the model as a result of the initial CFA [144, 187], which resulted in 5 items being removed from the original 20 item model. Two items were eliminated because of non-significant loadings on their respective constructs; Item 11, The term dementia should be avoided when discussing a diagnosis with a carer/family member, and item 16, Dementia is better treated by specialist physicians. An examination of modification indices revealed Item 12, Patients with dementia should be informed early so they can plan for the future, cross loading with a number of items, especially those reflecting the Attitude to *Care subscale.* As a result, Item 12 was moved to improve factor interpretability and model fit [174, 187]. While the initial decision to move item 12 was based on statistical criteria, an examination of the item also suggested conceptual congruity with Attitude to Care because it addressed perceptions of the benefits of early diagnosis and future care outcomes.

The construct Attitude to Communication was removed from the analysis because of the elimination of Item 11 (non-significant loading) as well as potential redundancy between the two remaining items (Item 13, *It is important to inform the person of the terminal course of the condition, and* Item 14, *It is important to inform relatives/family carers of the terminal course of the condition*. Bivariate correlations indicated redundancy (r=.760) and an examination of the items confirmed this. Both items related to the importance of informing the patient and family of the terminal course of the condition, with the only difference between the items being the subject. Finally, an examination of the standardised residuals identified potential misspecification of Item 9, *Guidelines for the management of dementia would greatly assist in providing care.* Examination of the item suggested that it reflected a desire for guidelines rather than an attitude to care. Removal of the item resulted in a significantly improved overall model fit. After the removal of redundant, cross-loading and mis-specified items, and improvements in factorability of the subscales a final 15 item, 3-factor model was confirmed.

The final 15-item, three-factor model (Figure 5 - 1) exhibited very good fit, confirming construct validity of the revised model, (x<sup>2</sup>=103.88; p=.105; RMSEA=.032; PCLOSE=.915; CFI=.967; TLI=.960). All items were significantly correlated to the construct, and modification indices were acceptable (r <.30), indicating no underlying significant relationships between items or constructs. Inter correlations between constructs were acceptable with coefficients below the .50 criteria [181]. The correlations between *Attitude to Care* and *Confidence in Clinical Abilities* was .11; *Attitude to Care* and *Frustrations* (.41). These results indicate minimal underlying correlations between constructs and clear discriminant validity.

#### Internal consistency

Total score for overall scale score ( $\alpha$  =.765) indicated acceptable internal consistency for a 15-item GPACS-D. Cronbach's alpha scores for two constructs reflected adequate internal consistency: *Confidence in Clinical Abilities* (a=.810); and *Attitude to Care* (a=.769). *Fears and Frustrations* (a=.450) exhibited a comparatively low internal consistency score. However, given the construct was defined by only three items, and because Cronbach's alpha is affected by the number of items that define a construct or latent variable , this may account for the low score and underestimate reliability [188].

#### Differences between groups

A comparative analysis was undertaken to determine whether the hypothesised sub scales could detect differences between different groups of GPs on the basis of exposure to dementia or experience as a GP. It was hypothesised that certain cohorts, because of their experience, would score higher than those with less experience or exposure to dementia. As shown in Table 5 - 2, GP Supervisors were more confident in their clinical abilities than GP Registrars (f=1.48; t=.283; p<.000), with similar results emerging for the *Fears and Frustrations* subscale (f=.447; t=4.72; p<.000). Additionally, those with prior professional experience of treating someone with dementia (irrespective of professional title) recorded a higher score for *Confidence in Clinical Abilities* (f=.332; t=4.26; p<.000) and *Fears and Frustrations* (f=.426; t=2.69; p<.008) than those who had not. No significant differences emerged for *Attitude to Care*. The overall summative score (combined total scores for *Confidence, Attitude to Care* and *Fears and Frustrations*) reflected these differences, with GP Supervisors and those who had professional experience with clients with dementia scoring significantly higher than GP Registrars (f=.396; t=6.26; p<.000), and those who had not treated clients with dementia in a professional capacity (f=.05; t=4.47; p<.000).

These findings suggest that the GPACS-D can differentiate between groups based on their level of exposure to, or experience of dementia, either from providing professional services, or being more experienced as GPs.

	Subscale mean scores/SD/total			
	Total mean score/SD/15	Confidence in Clinical Abilities/SD/5	Attitude to Care/SD/5	Fears and Frustrations/SD/5+
Alpha (a)	a=.765	a=.810	a=.765	a=.450
Role:				
GP Registrars (n=118)	9.96/1.21	2.66/.63	4.32/.45	2.98/.75
Supervisors (n=76)	11.1/1.30**	3.28/.76**	4.34/.41	3.49/.69**
Provided professional dementia care:				
Yes (n=162)	10.59/1.30**	2.99/.70**	4.36/.41	3.24/.77**
No (n=28)	9.41/1.26	2.37/.78	4.21/.52	2.83/.71

Table 5 - 2: Total and subscale scores (standardised) by role and experience

\*\* indicates a statistically significant difference at the .001 level of significance. T Test for independent samples.

+ Because of reverse scoring a higher score indicates less fear and frustration.





#### Discussion

The GPACS-D was developed over two distinct phases. Phase one involved the development and pilot testing of the GPACS-D and subsequent PCA to establish the preliminary validity of the scale and hypothesised subscales [185]. In phase two, described in this paper, I undertook a CFA to refine and finalise the scale as well as establish the construct and discriminant validity of each sub scale and the items reflecting them.
The final and validated GPACS-D survey comprises 15 items and 3 subscales; *Confidence in Clinical Abilities (6 items; a=.869), Attitude to Care* (6 items; a=.765) and *Fears and Frustrations* (3 items; a=.450). Each of the subscales confirmed in the model identifies specific aspects of attitude, confidence and frustrations implicated in the diagnosis and treatment of dementia. Both summative and subscale scores identified significant differences between groups, confirming the construct validity of the 15 item GPACS-D. Of note, supervisors and those who had provided professional service to people with dementia scored higher on all 3 subscales demonstrating that the scale is sensitive and applicable to analysis of differences in attitude to dementia care, confidence in diagnostic and clinical skills and frustration associated with treating dementia.

Our final model retained three of the four original constructs identified through PCA. *Attitude to Communication* was eliminated during the CFA modelling process due to redundancy and limited scope of the two remaining items. Communication has been identified as a key determinant in missed and delayed diagnosis and as an obstacle to effective doctor-patient communication about dementia [112]. Communication about dementia is complex and involves several players (GPs, people living with dementia, family members and other health care providers) and multiple issues ranging from difficulties in communicating a diagnosis, to poor literacy skills and cultural considerations [7]. It is likely that a more extensive, potentially stand-alone tool with a larger number of items would better address the complexity of these issues and identify elements of communication that can be targeted to improve communication between the physician, family, carers, and the person living with dementia.

The Attitude to Care and Fears and Frustrations subscales were independent of each other while the Fears and Frustrations subscale was moderately inversely related to Confidence in Clinical Abilities. Several surveys have been undertaken to investigate attitude and confidence of GPs in other areas of health care such as diabetes [189], drug use [190], smoking cessation [191] and health promotion [192]. Negative beliefs and lack of confidence when discussing unpleasant or time-consuming topics were reported [191] as were avoidance of more difficult discussions [190]. These studies emphasise how confidence and attitudes impact on GP approaches to health-related issues and that changing clinical practice is not simply a matter of increasing knowledge but also addressing how a GP's perceptions and beliefs affect their practice. Confidence in one's ability to undertake an action is also recognised as an important predictor of behaviour [40, 101], and has been identified as a barrier to diagnosing and treating dementia

[184]. Poor rates of diagnosis have been attributed to negative attitudes towards early diagnosis [118] and a reluctance to disclose [13, 108].

Regardless of attitudes towards the early diagnosis of dementia, a lack of confidence in clinical and management abilities may lead to avoidance of and delays in making a diagnosis. As with many people, health professionals tend to avoid those activities/behaviours for which they feel ill-equipped or exceed their capacity [23, 40], and within the context of dementia diagnosis and management, fears of professional inadequacy may contribute to frustration or avoidance of the condition resulting in low rates of diagnosis [30, 114, 115]. Avoidance of dementia may not be explicit but manifest in a reluctance to formalise a diagnosis, the preferential treatment of conditions for which treatment options are available, giving low priority to dementia symptoms compared to other health problems or avoiding care via the use of referrals because of a perception of having little to offer by way of treatment or cure[116]. Given that two of the items comprising the *Fears and Frustrations* construct align with avoidance, the construct may be more appropriately entitled 'avoidance' for the final version of the GPACS-D.

Improved education and training are often cited as the solution to poor diagnosis rates and management of dementia. However, the focus on knowledge and skills rather than behaviour and attitudes has been noted as a key gap in preparation for practice [132, 193]. As noted in other areas of health care, educational interventions need to address more abstract concepts such as nihilism, stigma and ageism as well as deficits in communication, disclosure and management skills [107].

Three of the four major factors identified by Bradford (2010) are covered by this tool including concepts relating to educational needs, attitudes towards dementia and approach to testing. All have been identified as factors contributing to either missed or delayed diagnosis of dementia [7].

The GPACS-D is a tool suitable to measure GP confidence and attitudes to dementia, which underpin behaviour change but confidence and attitudes are infrequently used as outcome measures in the evaluation of dementia educational outcomes [7].

#### Limitations

Attitude to Care was negatively skewed as evidenced by the high mean score. This suggests that the participating GPs may have a pre-existing and favourable

attitude towards engaging with dementia patients or that there is a form of social desirability bias at play [56]. As previous research has suggested, the impact of social norms in this group may account for self-reported favourable attitudes [56]. This point needs to be taken into consideration with self-administered surveys.

The internal reliability score for *Fears and Frustrations* was low and is partly a consequence of the small number of items that make up the subscale. The construct is relevant because it identifies concepts that arise as a response to managing dementia and is moderately associated with confidence. With respect to the communication subscale, the number of items left after model fitting was too low and the scope too limited to retain this subscale and should be addressed independently of this tool.

## Conclusion

The 15-item, three-subscale GPACS-D is a reliable and valid measure of GP confidence and attitudes towards dementia.

# Chapter 6 - The impact of dementia education

**Publication 3:** The effect of a Dementia Education Intervention on the confidence and attitudes of General Practitioners in Australia.

Mason, R., Doherty, K., Eccleston, C., Winbolt, M., Long, M. and Robinson, A., 2020. Effect of a dementia education intervention on the confidence and attitudes of general practitioners in Australia: a pre-test post-test study. *BMJ open*, 10(1).

## Precis

This chapter was published as an original research article in the peer-reviewed journal, British Medical Journal (Open) in January 2020, and describes the results of the administration of the GPACS-D to GP Registrars and GP Supervisors who attended dementia education workshops conducted throughout Australia. The aim was to assess the impact of these workshops on the attitudes and confidence of GP Registrars and GP Supervisors.

The final version of the completed manuscript in included here, with references listed at the end of this thesis.

## Abstract

*Objectives:* This study assessed the impact of a dementia education workshop on the confidence and attitudes of GP Registrars (GPR) and GP Supervisors (GPS) in relation to the early diagnosis and management of dementia.

Design: Pre-test post-test research design.

Setting: Continuing medical education in Australia.

Participants: 332 GP Registrars and 114 GP Supervisors.

*Interventions:* Registrars participated in a three-hour face to face workshop while Supervisors participated in a two-hour modified version designed to assist with the education and supervision of registrars.

*Main outcome measures:* The General Practitioners Confidence and Attitude scale for Dementia (GPACS-D) was used to assess overall confidence, attitude to care and engagement. A Wilcoxon signed ranks test was used to identify potential differences from pre-workshop (T1) to post workshop (T2) for each GP group. A Mann Whitney U test was undertaken to ascertain differences between each workshop group. A Cohen's d was calculated to measure the effect size of any observed difference between T1 and T2 scores.

**Results:** Significant increases in scores were recorded for 'Confidence in Clinical Abilities', 'Attitude to Care' and 'Engagement' between pre and post-test periods. GP Registrars exhibited the greatest increase in scores for Confidence in Clinical Abilities and Engagement.

**Conclusions:** Targeted educational interventions can improve attitude, increase confidence, and reduce negative attitudes towards engagement of participating GPs.

Article Summary

## Strengths and limitations of this study:

- the sample of Registrars and Supervisors is representative of the broader GP population in Australia [31];
- while the workshop for GP Registrars was compulsory this was not the case for GP Supervisors, thus a self-selection bias is possible;
- confidence, attitudes, and engagement were measured via GPACS-D, a validated tool.
- while each of the subscales included items relating to early diagnosis, the survey did not fully capture attitudes towards disclosure or perceived selfefficacy with regard to communication.

## Introduction

General Practitioners (GPs) are central to the early diagnosis and management of dementia [194]. Early diagnosis provides the opportunity for patients, carers and family to be informed about the condition, its prognosis, treatment options and support [195, 196] and allows the patient to plan for their future and be active participants in decision-making [186, 197].

Obstacles to timely diagnosis and intervention may include a lack of diagnostic tests/certainty [12] and lack of confidence in diagnostic skills and management [25], while negative attitudes towards diagnosis, disclosure and treatment [16, 22, 24] may also affect diagnosis rates. Further, stigma may delay recognition and diagnosis through concealment, minimisation or dismissal of early signs and symptoms [13]. Patients often present with co-occurrent conditions, further complicating the clinical picture [120, 196].

It is estimated that one third of GPs lack confidence in their diagnostic skills, while two thirds lack confidence in the management of behaviours associated with dementia [25], or feel they have little or nothing to offer patients presenting with dementia [113], with a third of GPs failing to routinely disclose the diagnosis [18, 25, 28]. Relatedly, pessimism surrounding dementia prognosis, and inability to offer curative treatment [105] may lead to an attitude of 'therapeutic nihilism' among GPs [13, 25], which reflects a biomedical definition of treatment and an ethos centred around curing people [105], while simultaneously ignoring therapeutic interventions that may benefit people with dementia and their carers [7, 106, 107].

lliffe (2003) argues that low rates of dementia diagnosis are not only a result of knowledge and skills deficits but also failure to transfer acquired knowledge into clinical practice [22]. Relatedly, Boise et al. (2005) state that attitude rather than knowledge is a key determinant of whether GPs undertake a full assessment [195], and others argue that the diagnostic and management practices of GPs towards dementia may be significantly affected by underlying beliefs and attitudes [27, 37]. While social psychological theory suggests a relationship between perceptions of self-efficacy and effort, and avoidance [102], GPs' hesitancy to diagnose dementia may not be explicit. Rather it may manifest in a reluctance to formalise a diagnosis or preferentially treat co-occurring conditions for which treatment options are available [16, 112], referring on because of limited treatment options [116],

questioning the (traditional) role of the GP in treating dementia [117], or having insufficient resources [18].

Changing attitudes towards the early diagnosis of dementia has been identified as a significant task for medical educators, with the key to countering such attitudes being targeted educational campaigns [108]. Moreover, evidence suggests that the focus of GP training around dementia should encompass more than knowledge acquisition and aim to improve confidence and attitude [198]. While GP attitudes toward caring for people with dementia have been shown to be positive [184], fear of misdiagnosis [12] and lack of confidence in diagnostic and dementia management skills have been reported to be of particular concern in multiple studies with a lack of effective education and training frequently cited as an underlying cause [25, 27, 30].

Comprehensive dementia education for GPs should include epidemiological knowledge, communicating a diagnosis, symptom management, and support services for patients and their carers [114, 132]. Tullo (2011) emphasises the importance of personhood, quality of life and communication with patients [133], while Phillipson (2015) argues that training interventions should place an emphasis on the slow progression of the condition, the treatments available, and maintenance of quality of life [135].

In Australia, GPs typically are trained in an apprenticeship model with a key aspect of training involving experienced GP Supervisors providing support to the GP registrar (GPR) within a general practice setting. GP Supervisors facilitate registrar learning through identifying learning needs, encouraging reflective learning and practice, guiding access to resources, providing advice on applying knowledge to specific patient cases and role modelling interactions with patients (22).

Tailored training workshops were developed specifically to augment this interaction and address dementia specific training needs. Directed at both GP Supervisors and GPRs, we have previously shown them to be effective in improving dementia knowledge [31]. Here we examine the impact of these workshops on attitudes and confidence toward dementia with a view to improving management of dementia in general practice.

#### Method

#### Study aims and design

In Australia, GP Registrars are required to engage in a learning program consisting of a number of learning units conducted by regional training providers in each state. "The Recognising, Diagnosing and Managing Dementia in General Practice" workshop was developed by the Wicking Dementia Research and Education Centre as a response to the expressed absence of appropriate dementia related content in GP Registrar training programs. The workshop consists of two 1.5-hour face to face presentations delivered by medical educators focusing on (a) recognising and diagnosing dementia and (b) managing dementia in General Practice, while the Supervisor's workshop is a modified version of that delivered to Registrars that seeks to support Supervisors to teach registrars the diagnosis and management content provided in the registrar program as discussed elsewhere [31]. The strong focus on providing a framework for decision making for the recognition, diagnosis and management of dementia is complemented by tools and resources that are aimed at improving both diagnostic capacity and providing ongoing care and support for people with dementia and their family and/or carers. There is a stronger focus on the lived experience of dementia and more in-depth coverage of some aspects of dementia diagnosis and management in the Registrar's workshop than in the Supervisor's workshop.

#### Participants

GPs were recruited from dementia education workshops conducted in four Australian States between 2014 and 2017. The sample comprised two cohorts; those who undertook the GP Registrar's workshop (n=332) and those who undertook the Supervisor's workshop (n=114).

#### Process and measures

All workshop participants were invited to complete the GPACS-D survey [38] immediately before (T1) and immediately after (T2) the workshop. Participants were provided with an information sheet about the research, were informed that the survey was entirely voluntary and that completion of the survey implied consent. The impact of the workshops on confidence and attitude was measured using the GPACS-D which comprises 3 subscales; *Confidence in Clinical Abilities* (6 items), *Attitude to Care* (6 items) and *Engagement* (3 items) and validated using confirmatory factor analysis [199]. A Likert scale was employed scoring from 1

(strongly agree) to 5 (strongly disagree). Total subscale scores were standardised with a minimum score of 1 and a maximum score of 5 so that comparisons could be made between subscales [40].

## Analysis

We were interested in the impact of the respective workshops on GP Registrars (GPRs) and GP Supervisors. We hypothesised that the Supervisor group would differ from the GPR group in attitude and confidence given their experience as practicing GPs.

Non-parametric tests were employed to identify differences between groups (Mann Whitney U test for independent samples) and between time points for each group (Wilcoxon signed ranks test for paired samples). Cohen's d was calculated to measure the effect size of any observed difference between T1 and T2 scores for each group with d=0.2 equivalent to a 'small' effect size, 0.5 a 'medium' effect size and 0.8 a 'large' effect size [183]. All data analyses were conducted using SPSS (Version 22).

## Ethics approval

A University Human Research Ethics Committee reviewed and approved this study (Reference Number: H0012046). Before the workshop commenced, the study was described to participants and all participants were given an Information Sheet. Return of the completed surveys at the end of the workshop implied their consent for use of the data.

## Patient and public involvement

There was no patient or public involvement in this study.

## Results

A total of 446 respondents were included in the analysis comprising 332 attendees at GP Registrar workshops (the GPR group) and 114 attendees from the Supervisor workshop (the Supervisor group) (see Table 6 - 1). Supervisors were significantly older than GPRs (U=2542; z=13.065; p<.000), and more had undertaken prior dementia education ( $x^2$ =20.263; p<.000), although this proportion was small for both groups. More Supervisors had provided professional care to someone with dementia than GPRs ( $x^2$ =11.294; p=.001), while similar proportions of both groups had a family member with dementia.

Table 6 - 1: Sample cha	racteristics
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Demographics	GP Registrars (n=332)	Supervisors (n=114)
Age	33.03 (SD=6.1)	49.8 (SD=10.5)
Male	40.2% (n=129)	50% (n=56)
Australian born	41.9% (n=139)	39.5% (n=45)
Previous dementia training	5.6% (n=18)	20% (n=22)
Provided professional care	87% (n=280)	98% (n=108)
Family member dementia	35.5% (n=114)	38.2 (n=42)

The GPACS-D assessed the impact of each of the workshops on three constructs; *Confidence in Clinical Abilities, Attitude to Care* and *Engagement.* 

## Confidence in clinical abilities

Items in the *Confidence in clinical abilities* subscale reflect a GP's perceptions of their capacity to diagnose, treat and manage dementia. Analysis of scores for each of the items comprising this subscale is shown in Table 6 - 2.

While both GPRs and Supervisors were significantly more confident after the workshops), Supervisors were significantly more confident in their clinical abilities than GPRs both before (U=9462; z=7.707; p<.000) and after their respective workshops (U=10962; z=5.327; p<.000), GPRs exhibited a significantly greater improvement in score than Supervisors (U=12051; z=4.014; p<.000), while the effect size of the change in *Confidence in clinical abilities* was strong for both groups and greatest for GPRs. Supervisors recorded a higher level of confidence than GPRs on all items both before and after the workshop, although both groups improved significantly across all items (Table 6 - 2). GPRs exhibited larger score changes on all items after the workshop.

Confidence in Clinical Abilities	Role	Pre-test mean score(±SD)	Post-test mean score(±SD)	Z	Р*	Cohen's D
Overall score	GPR	2.67(0.62)	3.69(0.57)	15.04	<.000*	1.710
	GPS	3.28(0.75) +	4.03(0.53) +	8.17	<.000*	1.150
Frustration at not being	GPR	2.49(0.93)	3.55(0.87)	12.24	<.000*	1.177
people with dementia	GPS	2.94(1.13)	3.94(0.84) +	6.96	<.000*	1.004
Confident in ability to	GPR	2.32(0.94)	3.25(0.88)	12.28	<.000*	1.021
discuss legalities	GPS	2.96(1.08)+	3.60(0.92)+	4.97	<.000*	0.637
Confidence in ability to	GPR	2.65(0.82)	3.82(0.71)	13.87	<.000*	1.525
diagnose	GPS	3.31(0.88)+	4.18(0.61)+	7.48	<.000*	1.149
Confident in ability to	GPR	2.86(0.78)	3.80(0.69)	13.24	<.000*	1.276
provide medical care	GPS	3.52(0.88)+	4.21(0.56)+	6.67	<.000*	0.935
Confident in ability to	GPR	2.70(0.78)	3.70(0.71)	13.41	<.000*	1.340
symptoms	GPS	3.23(0.87)+	3.95(0.71)+	6.52	<.000*	0.906
Confident in knowledge of	GPR	2.43(0.84)	3.47(0.89)	13.03	<.000*	1.201
local resources	GPS	3.04(0.92)+	3.79 (0.83)+	6.88	<.000*	0.856

Table 6 - 2: Confidence in clinical abilities; pre and post workshop score.	s by r	role
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GPR (Registrar), n=332; GPS (Supervisor), n=114.

+Indicates a significant difference between groups at the .05 level of significance (Mann Whitney U test for independent samples).

\* Indicates a significant difference between pre and post intervention periods at the .05 level of significance (Wilcoxon signed ranks test for paired samples).

Supervisors reported a higher score for 'confidence in ability to diagnose dementia' after the workshop (u=12477; z=4.643; p<.000) than GPRs. However, only 13.8% of GPRs were confident in their diagnostic ability before the workshop compared to 44.2% of Supervisors, rising to 60.4% GPRs post workshop compared to 62.6% post for Supervisors.

Confidence in 'ability to provide appropriate medical care' also increased significantly for both groups, with Supervisors recording a higher mean score both before and after the workshop (U=11599; z=5.455; p<.000), while a strong effect size was observed for score changes in both groups (GPR, d=1.276; Supervisors, d=.935). An increase in the proportion of GPRs agreeing with the statement (18.7% to 59.8%) was observed after the workshop.

Confidence in 'providing advice about managing dementia related symptoms' improved markedly for both groups, with Supervisors recording a significantly higher score than GPRs (U=13804; z=3.182; p<.001). Only 13.8% of GPRs were confident pre-workshop increasing to 56.3% post workshop, with 9.5% strongly agreeing. Before the workshop 48.5% of Supervisors agreed that they were confident in providing advice (8.8% strongly agreed), increasing to 67% after the workshop (27.4% strongly agreed).

#### Attitude to care

Items in the *Attitude to Care* subscale reflect aspects of the provision of care for patients and their families. Analysis of scores for each of the items comprising this subscale is shown in Table 6 - 3.

#### Table 6 - 3: Attitude to care; pre and post workshop scores by role

Attitude to Care	Role	Pre-test mean score(±SD)	Post-test mean score(±SD)	Z	P**	Cohen's D
Querall score	GPR	4.35(0.43)	4.70(0.40)+	12.98	<.000*	0.840
Overall score	GPS	4.35(0.44)	4.59(0.40)	6.37	<.000*	0.570
Much can be done to	GPR	4.22(0.71)	4.54(0.61)	6.98	<.000*	0.483
improve lives of patient	GPS	4.37(0.65)	4.61(0.54)	4.43	<.000*	0.401
Early detection benefits	GPR	4.32(0.74)	4.73(0.59)+	8.38	<.000*	0.612
the patient	GPS	4.21(0.84)	4.52(0.73)	3.92	<.000*	0.393
Important family/carers	GPR	4.56(0.58)	4.81(0.47)+	6.98	<.000*	0.473
seek external support	GPS	4.52(0.61)	4.67(0.53)	2.69	<.000*	0.262
Important family carers	GPR	4.38(0.67)	4.69(0.54)	7.92	<.000*	0.509
contact Alzheimer's Aust.	GPS	4.42(0.69)	4.64(0.57)	4.01	<.000*	0.347
GPs in best position to	GPR	3.95(0.82)	4.40(0.70)	9.41	<.000*	0.59
organise care	GPS	4.06(0.87)	4.44(0.66)	4.68	<.000*	0.492
Patients should be	GPR	4.31(0.72)	4.82(0.51)+	9.92	<.000*	0.817
plan for the future	GPS	4.28(0.77)	4.62(0.75)	4.25	<.000*	0.447

GPR (Registrar), n=332; GPS (Supervisor), n=114.

+Indicates a significant difference between groups at the .05 level of significance (Mann Whitney U test for independent samples).

\* Indicates a significant difference between pre and post intervention periods at the .05 level of significance (Wilcoxon signed ranks test for paired samples).

Overall mean scores for *Attitude to Care* were equivalent for Supervisors and GPRs prior to the workshops and increased significantly for both GPRs and Supervisors following the workshop, with moderate effect sizes for the increases (Table 6 - 3). GPRs scored significantly higher than Supervisors post workshop (U=13896; z=2.578; p=.010).

Significantly higher mean scores were reported for GPRs compared to Supervisors for 'early detection benefits the patient' (z=3.21; p<.000) and 'Patients should be informed early, so they can plan for their future' (z=3.26; p=<.000; Table 6 - 3).

Both groups reported significant increases in agreement that 'early detection of dementia benefits the patient', which had a moderate effect size for GPRs and a weak effect size for Supervisors. The greatest difference reported was for those strongly agreeing. GPRs recorded an increase in those strongly agreeing (from 47.3% pre-workshop to 77.9% post workshop) compared to an 18 % increase for Supervisor's (44.2% to 62.6%) post workshop. Similar results were obtained for the item 'Patients with dementia should be informed early so they can plan for the future'. While both groups reported significant increases in those agreeing with the benefits of informing patients early, GPRs had significantly higher scores than Supervisors post workshop (4.82 versus 4.62; z=3.26; p=.001) and recorded a larger increase in score. A change with a strong effect size was observed for GPRs and with a moderate effect size for Supervisors.

Both GPR and Supervisor groups recorded increases in those agreeing that 'it is important that relatives/family/carers of dementia seek external support'. The post workshop mean score for GPRs was greater than for Supervisors (z=2.99; p<.003), while GPRs also exhibited the greatest improvement.

#### Engagement

*Engagement* measures a GP's perceptions towards treating dementia, and includes fear of communicating a diagnosis, frustration in managing dementia and a preference for treating other conditions (Table 6 - 4).

Both Supervisors and GPRs recorded a significantly higher score for *Engagement* post workshop, while Supervisors reported greater *Engagement* than GPRs at baseline (U=12055; z=5.549; p<.000) and after the workshop (U=11338; z=5.135; p<.000). A moderate effect size was observed for the score change shown for each group.

Engagement	Role	Pre-test mean score(±SD)	Post-test mean score(±SD)	Z	Р*	Cohen's D
Overall score	GPR	2.98(0.70)	3.42(0.74)	10.25	<.000*	0.610
	GPS	3.44(0.76)+	3.84(0.74)+	6.16	<.000*	0.530
Managing dementia is	GPR	3.00(.85)	3.51(0.94)	8.24	<.000*	0.569
frustrating	GPS	3.45(1.02)+	3.91(0.83)+	4.36	<.000*	0.494
Fear of communicating a	GPR	3.88(0.98)	4.14(0.89)	4.78	<.000*	0.277
diagnosis	GPS	4.16(0.97)+	4.53*(0.73)	3.43	<.000*	0.431
Preference for treating	GPR	2.77(0.96)	3.20(0.99)	7.83	<.000*	0.440
other diseases	GPS	3.27(0.97)+	3.64(0.95)+	4.47	<.000*	0.355

Table 6 - 4: Engagement; pre and post workshop scores by role

GPR (Registrar), n=332; GPS (Supervisor), n=114.

+Indicates a significant difference between groups at the .05 level of significance (Mann Whitney U test for independent samples).

\* Indicates a significant difference between pre and post intervention periods at the .05 level of significance (Wilcoxon signed ranks test for paired samples).

Supervisors recorded significantly higher mean scores for each of the 3 items comprising engagement at both pre and post workshop periods.

Both GPR and Supervisor groups reported less frustration managing dementia post workshop, while Supervisors exhibited significantly less frustration at both pre and post workshop periods (u=12909; z=3.910; p>.000) than GPRs. The greatest improvement was reported by GPRs, with moderate effect sizes exhibited for both groups. The proportion disagreeing with the statement that 'dementia was frustrating to manage' increased from 19.5% to 39.4% for the GPR group which was similar magnitude of change to Supervisors (31% to 50.5%). However, a significant proportion of both groups were still undecided about this statement post workshop (GPRs 33.1%,19.6% Supervisors). As with other aspects of the subscale, Supervisors reported less fear of communicating a diagnosis than GPRs at both pre and post workshop periods (u=12465; z=4.458: p<.000) with a moderate effect for Supervisors and a weak effect for GPRs.

Similar results were obtained for a preference to treat other diseases, with both groups recording significant improvement after the workshop. Supervisors recorded a higher mean score than GPRs at both pre and post workshop periods (u=12868; z=3.906; p<.000), while GPRs exhibited the greatest increase, with moderate effect observed for both groups. The proportion of GPRs agreeing to a preference for treating other diseases decreased from 32% pre-workshop to 18.6% post workshop, compared to 18.6% to 10.3% for Supervisors. However, a large proportion of each group were neutral to the statement before and after the workshop, with a decreased proportion of Supervisors (42.5% pre, 32.7% post) and a relatively unchanged proportion of GPRs (38.1% pre, 39% post) reporting neutral views on this item.

## Discussion

This study examined the impact of tailored dementia education workshops on the attitudes and confidence of both GP Registrars and GP Supervisors towards dementia.

Attending tailored workshops resulted in significant improvements in attitudes, confidence, and engagement of both groups. While increased confidence and reduced negative attitudes towards the management of dementia have previously been reported to correlate with a self-reported history of prior dementia training [7], unlike others this study demonstrates a direct and immediate impact of a training intervention.

In some respects the predisposing positive *Attitude to Care* and improvement post workshop was not surprising given that GPs are reported to have a positive attitude with respect to their role in providing care and early diagnosis for people with dementia [184, 200]. Indeed, our findings highlight the effectiveness of the workshop's focus on early warning signs, and the importance of diagnosis and management approaches, which are intended to influence participants to more effectively engage people with dementia and their families. These results suggest that workshop attendance is useful in preparing GP Registrars for practice and experienced GPs who act as their Supervisors.

The confidence of the GP Registrar group, while not as high as Supervisors, significantly improved post workshop, albeit from a notably low level which provides insight into the implications of the traditional bio-medical focus of much medical education [105], often with minimal focus on therapeutic interventions [7, 106, 107]. Differences in pre-test confidence between the cohorts are not surprising given GPRs are generally younger and less experienced [27]. The greater magnitude of change for GP Registrars in this study would suggest that elements of the workshop, especially diagnostic skills, providing appropriate medical care

and managing dementia related symptoms, may particularly impact on confidence, again highlighting its applicability to GP specialty training.

However, it is interesting that only 44% of Supervisors reported confidence to diagnose dementia pre workshop, rising to only around 60% post workshop. Similar findings were evident in the items related to confidence providing advice and appropriate medical care. It was also notable that at both pre and post workshop periods Supervisors had more negative attitudes to the benefits of early diagnosis. This finding may be influenced by the Supervisors underlying beliefs and attitudes [27, 37], which in turn may delay diagnosis in practice given attitudes rather than knowledge have been identified as a key determinant of whether GPs undertake a full assessment [195]. Addressing these gaps is essential if GP Supervisors are to effectively support GPRs to develop their dementia diagnostic and management skills in the clinic in the context of apprenticeship model of GP training utilised in Australia [127, 201].

A positive impact on engagement was also observed with both groups recording significantly improved scores after each of the workshops. The higher score for the GP Supervisors group may in part reflect their level of exposure and experience to dementia. However, it is concerning that pre workshop only 31% of Supervisors disagreed with the statement 'dementia is frustrating to manage', with 19.5 % of GPRs disagreeing. While these scores improved post workshop this does suggest a high level of frustration [40]. Indeed, the literature suggests GPs' perceptions of their capacity to diagnose, communicate a diagnosis and manage dementia may impact on the extent to which they engage with a person with suspected or actual dementia or how much effort they apply to it [40].

Of note, GPRs commenced the workshop with a low likelihood of having experienced any prior dementia training, despite 87% having provided professional care to people with dementia, with a similar experience for supervisors. The lack of training certainly has implications for the GPs' knowledge of dementia, as we have previously demonstrated [1]. Results reported recently suggest that particularly for GPRs, the workshop increases their base knowledge of dementia [1] together with their confidence levels as demonstrated in this analysis.

Improved knowledge, in association with enhanced confidence and attitude suggests that tailored workshops have the potential to not only increase diagnosis rates and improve management of dementia but also enhance in-practice training

particularly where both Registrar and Supervisor have received targeted dementia training.

## Conclusion

Targeted educational interventions can improve attitude, increase confidence, and reduce negative attitudes towards engagement of participating GP registrars and supervisors. Findings highlight a clear need for GPs to have access to targeted workshops especially given the growing numbers of people with dementia.

## Supplementary analysis

The data used to provide this analysis comprised participants (GP Registrars and Supervisors) who attended the dementia education workshops described above. As part of a larger study the knowledge of participants was measured in this group and reported in Tierney et al[31]. This provided an opportunity to compare knowledge data with the subscales contained in GPACS-D, which had not been previously undertaken. The Dementia Knowledge Assessment Scale (DKAS), a validated scale, was used to assess overall dementia knowledge as well as knowledge on four subscales (*Causes and characteristics; Communication and behaviour; Care considerations; Risks and health promotion*).

The method used to collect the data was the same as noted in the method section of this chapter, that is, participants completed the DKAS and GPACS-D immediately before and after the workshop. Overall DKAS scores were then correlated with each of the subscales contained in the GPACS-D to identify any significant relationship between knowledge, confidence in clinical abilities, attitudes to care and engagement, and the strength of these relationships.

Table 6 - 5 presents the bivariate correlations measuring the effect of knowledge (DKAS) on Attitude to Care, Confidence in Clinical Abilities and Engagement. Additionally, the table also displays the effect of Attitude to Care, Confidence in Clinical Abilities and Engagement.

#### Results

As can be seen dementia knowledge was significantly associated with *Attitude to Care* (r=.159; p=.001) and *Confidence in Clinical Abilities* (r=.125; p=.012). Further, *Attitude to Care* was significantly but modestly associated with *Engagement* 

(r=.099; (p=.038), while *Confidence in Clinical Abilities* was significantly associated with *Engagement* (r=.356; p=.000).

Variables		Attitude to Care	Confidence in Clinical Abilities	Engagement
DKAS Total	r'	0.159	0.125	0.074
	р'	0.001	0.012	0.136
	n'	406	405	406
Attitude to Care	r'		0.082	0.099
	р'		0.086	0.038
	n'		438	440
Confidence in Clinical Abilities	r'			0.356
	р'			0.000
	n'			439

Table 6 - 5: Bivariate correlations; DKAS and GPACS-D

#### Conclusion

Recent research has reported on the impact of knowledge on rates of dementia diagnosis and management outcomes [31], while research for this thesis highlights the impact of confidence and attitudes on the diagnosis and management of a person with dementia. What can be seen from this supplementary analysis is the impact knowledge has on confidence in clinical abilities and attitudes towards the care of someone with dementia. While each of the correlations was modest, increases in dementia knowledge appear related to positive increases in attitude to care and confidence in clinical abilities. Thus, the more knowledge GPs possess the more positive their attitude and the greater their confidence. Further, the more confidence a GP has, the more positive they are in relation to their attitude towards engagement. Therefore, whilst knowledge is of obvious importance with regards to a clinician's capacity to diagnose and manage dementia, the results indicate that knowledge does not operate in isolation, but also (has a relationship with) influences attitudes towards care and perceptions of clinical capacity to diagnose and manage dementia. In the absence of treatment options, GPs are more reliant on appropriate access to support services.

## Chapter 7 - Discussion

This thesis has presented the development, refinement and application of the GPACS-D, a new tool that has enabled measurement of attitudes and confidence of GPs with regard to dementia, and importantly, demonstrated the impact of education on these attributes.

#### Measuring attitudes and questionnaire development

The first aim of this thesis was to develop the GPACS-D instrument. The literature reveals several questionnaires and surveys that address confidence and/or attitudes of practitioners. These studies informed the development of a preliminary list of items, used to explore the attitudes of GPs towards diagnosis and care, as well as perceived self-efficacy with regard to the clinical skills required to both diagnose and manage dementia [90]. However, these instruments were not fit for purpose because they were not developed to measure the impact of an educational intervention on the confidence and attitudes of GPs. Therefore, this thesis sought to develop a valid and reliable tool that would complement the use of the DKAS knowledge tool, in order to gain a fuller understanding of the relationship between knowledge, confidence and attitude, and ultimately the effectiveness of an education intervention in supporting GPs to develop the capability to effectively diagnose and manage dementia.

As outlined in the thesis publications the GPACS-D tool was developed and validated through several stages where several criteria needed to be met for the tool to be deemed a valid and reliable measure [144, 158, 205]. Engagement with a panel of experts suggested that GPs should have the capacity to diagnose, manage, and provide referrals and support to both patients, and the family of someone with dementia. The individuals that comprised the expert panel were a valuable resource in establishing the focus and content in developing the GPACS-D. As previously stated, the goal was to generate a tool that was reliable, sensitive to change and adequately and accurately captured the constructs of attitudes and confidence [150, 178, 206]; a tool that when applied could provide an evidence base on GP attitudes to the diagnosis and management of dementia.

As outlined above we employed principal component analysis (PCA) as an exploratory technique to identify underlying structures in the data from which we could derive potential themes or factors. The four potential subscales arising from the PCA were (a) *Confidence in clinical abilities*; (b) *Support for early diagnosis,* 

quality of life and care; (c) Fears and frustrations; and (d) Communication about dementia progression. These subscales encapsulate different dimensions of the interaction of the GP and their patient and comprised the preliminary model for GPACS-D.

An important step in the process of creating a valid and reliable tool was to confirm that the tool was suitable for measuring attitudes and confidence and that the preliminary model could be defended. As reported in Chapter 5 the preliminary model was refined using CFA and, in the process, further refinement resulted in elimination of the 'Communication about dementia progression' subscale. This rigorous process of item selection and refinement resulted in the final survey which comprised three subscales 'Attitude to Care', 'Confidence in Clinical Abilities' and 'Engagement'.

The final model did not retain the *Attitude to Communication* subscale. While several items related to communication were initially included, they did not form a discrete construct. Communication has been identified as a key barrier in the diagnosis and management of dementia [7, 129], with research indicating that GPs may be reluctant to discuss a diagnosis with patients for any number of reasons including their attitude towards the benefits of timely or early diagnosis, a fear of misdiagnosis, damage to the doctor-patient relationship, general communication problems and discomfort in discussing difficult issues. Communication is a key contributor to the disclosure of dementia diagnosis and the ongoing interaction with the patient and their family. Given we removed the *Attitude to Communication* subscale, determining how effective education is in improving attitudes towards, and confidence in, communication skills warrant further investigation.

The inclusion of additional items such as GP perceptions of their role in communicating a diagnosis, delivering 'bad' news, attitude towards discussing a diagnosis with patients *and* carers/family, the patient's right to know and acting in the patient's best interest with regard to disclosure, may have improved both the internal consistency and utility of the construct.

## Educational interventions and measuring change

A key reason why the GPACS-D was developed was to determine whether dementia-focussed educational interventions contribute to positive changes in GPs' attitudes and confidence. The tool subscales provide a more in-depth understanding of the specific attributes GPs hold and any subsequent changes in their attitudes, confidence, and engagement toward patients with dementia. In turn this level of specificity can for the first time illuminate opportunities to target specific issues related to GPs' respective confidence, attitudes and engagement that can effect positive change in clinical practice and enhance the quality-of-care people with dementia and their families receive.

The GPACS-D also provides an opportunity for the first time to develop an evidence base of attitudes and confidence GPs have towards dementia. It also allows us to compare the attributes of different GP cohorts. Using the GPACS-D to measure attitudes and confidence among GP Supervisors and GPRs attending dementia workshops provided an opportunity to examine their relative status with respect to attitudes and confidence, as well as the effectiveness of these workshops in facilitating positive changes among the two cohorts. This remains a key strength of the GPACS-D; its capacity to, for the first time, not only quantify GP attitudes and confidence towards the diagnosis and management of dementia, but also how different cohorts compare, and to gauge the effectiveness of interventions aimed at improving these abilities.

The workshops were designed to address some important gaps in dementia education for GPs and the findings presented in this thesis provide evidence of the workshop's effectiveness in delivering a positive improvement in the confidence and attitudes of both GPRs and GP supervisors.

Of interest, we were also able to quantify differences between GPRs and GP Supervisors in their responses to the workshops, in key areas such as diagnostic abilities, attitudes towards early diagnosis and level of engagement. As outlined in the findings of Chapter 6, the GPR group recorded the greatest change following the workshop in the areas of confidence and engagement. Similar differences were also found at baseline and, as argued, were related to clinical experience or prior education [207]; GP Supervisors and GPRs with prior training reported a higher score for all subscales. There was a clear indication that participation in dementia education is a means to positively impact attitudes and confidence in both experienced and inexperienced GPs, and importantly even those with considerable experience benefit from ongoing education. The effect of the workshops on knowledge was also available from the larger study; therefore, we were able to undertake some additional analysis of the relationship between confidence, attitudes, and knowledge in this group. The case for GP Supervisor involvement in dementia education is compelling. As the literature attests, supervisors are crucial in not only providing registrars with the experience they need in the diagnosis and management of dementia in the clinic, but also in supporting them to further develop their diagnostic and management skills in general practice [208]. Interestingly we demonstrated that GPRs had a more positive attitude towards the benefits of early diagnosis than did GP Supervisors which in some ways is concerning given the importance of early diagnosis and the critical role Supervisors play in supporting the practice development of new GPs [125, 127]. Arguably, the GPRs' more positive attitude to early diagnosis may, in part be due to recent medical graduates being exposed to results from clinical trials and the extensive accumulated evidence that risk factors for dementia and dementia progression include lifestyle, psychosocial and biomedical factors [209]. In this context ongoing education is vital to keep abreast of recent advances and the increased number of risk factors being identified in order for GPs to not only detect and diagnose dementia, but also to prevent it [5]. This is clearly an important priority for GP Supervisors given their crucial role in developing the discipline [210].

Indeed, given the role GP Supervisors have in the GPRs' professional development, it is also arguably important to address issues related to confidence, attitudes and engagement exposed in this study if Supervisors are to effectively support GPRs in developing the requisite skills to diagnose and manage people with dementia in general practice. For example, a recent Australian study indicated that GPRs were more likely to seek help from their supervisors to assist them in managing patients with mental health conditions (including dementia), which they found difficult to deal with [208]. This further emphasises the crucial role that GP Supervisors play in the development of clinical skills to deal with mental health issues and degenerative neurocognitive conditions such as dementia, an area where GPRs experience difficulty. Registrars in general practice are reported to have limited exposure to those over 65, with only 17% of their patient interactions in this group compared with 30% of GP interactions [211], and when they do it is for different or less complex conditions. GPRs experienced less clinical exposure to older patients with chronic conditions and a lack of opportunity in continuity of care [211]. Supervisors' knowledge and confidence in their own clinical capacity as well as their attitude towards diagnosis and care of people with dementia can potentially impact on the quality of training a GPR receives in the clinic. This point emphasises the importance of Supervisors' ongoing engagement in education and the important role that Supervisors play in providing quality clinical experiences

for GPRs [208]. The GPACS-D now provides a mechanism to evaluate the effectiveness of any such interventions designed to support this process.

The literature reveals that GP confidence has been identified as an important factor in relation to the likelihood of early diagnosis [212, 213], with a lack of confidence possibly leading to avoidance or delay in making a diagnosis [7]. Education and health literature indicate that knowledge correlates with both attitudes [30, 123] and perceptions of self-efficacy [39], suggesting that poor knowledge contributes towards low self-confidence and potentially, generation of negative attitudes towards diagnosis and or care. In this study, a relationship was observed between knowledge and two of the GPACS-D subscales; Attitude to Care and Confidence in Clinical Abilities, while no relationship was observed between knowledge and Engagement, although Engagement correlated with Confidence in Clinical Abilities. The relationship between Confidence in Clinical Abilities and Engagement suggests that improvements in confidence may also have the potential to improve engagement. Our results for the first time indicated that while both Registrars and Supervisors held a relatively positive attitude towards early diagnosis and associated benefits, with respect to diagnostic ability and capacity to provide medical care or advice relating to the behavioural symptoms of dementia their confidence was 'low'. The literature highlights GP reports of deficiencies in diagnostic and dementia management skills [25, 27, 30], and our results indicate a relationship between confidence in clinical abilities and attitude towards engagement, suggesting that by increasing confidence we can potentially improve attitudes towards engaging patients with dementia. Therefore, education that improves confidence and provides the requisite training may ameliorate avoidance behaviours [116] and encourage greater engagement of the GP with the person presenting with dementia.

This study demonstrates that attitudes and confidence towards dementia can be improved through appropriate educational interventions. Changing the practice behaviours of GPs towards dementia requires their involvement in evidence based educational programs that address not only knowledge and skills deficits [35, 39], but also attitudes and confidence [34], and in doing so, potentially improve GP effectiveness in the detection, diagnosis and management of dementia.

A small proportion of Registrars and Supervisors in this cohort indicated that they had previously undertaken dementia training [31, 82]. Despite recent medical graduates reporting a lack of confidence, inadequate preparation and specific skills required to undertake clinical practice, including those required for the

management of dementia [80], and despite education being most frequently identified as the pathway to improved practice, providing this education to a cohort of practitioners already burdened with significant time constraints remains challenging. There was notable variability in knowledge of dementia among both Registrars and Supervisors in relation to both overall dementia knowledge score and the various domains of dementia. Knowledge, confidence, and attitude scores indicate that there is room for improvement and requires changes in the way that dementia education is provided that ensures Supervisors and Registrars engage in and benefit from training opportunities. In this regard, innovations such as integrated workplace learning and interprofessional team-based learning that provide registrars with workplace learning experiences in patient centred primary care may be useful in effecting practice change [214].

While skills-based training is useful for raising awareness, knowledge, and skills, research has indicated that the impact on attitudes regarding diagnosis and management has been limited [35]. This has been attributed to a lack of opportunity to practice specific assessment skills, while others have suggested that multifaceted interventions involving training and individual coaching have been effective in modifying behaviour and producing lasting change [130]. Research highlights that educational interventions are limited in their effectiveness in changing attitudes and behaviour and that to achieve lasting change a combination of approaches may be required [81]. Future studies might examine the long-term impact of different educational approaches on confidence, attitudes or clinical behaviour and warrants further research.

A combination of negative attitudes, low confidence, and poor knowledge is likely to impact on a GP's management of dementia, and as a result their capacity to improve diagnosis rates but also potentially, management outcomes.

A lack of knowledge and low self-efficacy has implications in relation to current medical curricula at both undergraduate and postgraduate levels to address these issues, which have been identified by GPs themselves [30, 114]. Opportunities exist to improve the education of students and registrars to ensure that they are prepared for this growing patient group.

## Significance and impact

Many educational initiatives fail to be thoroughly and systematically evaluated across meaningful parameters. Whilst quizzes or estimates of knowledge are relatively common, other measures which might underpin the behaviour change intended to be initiated by education, such as confidence and attitudes, are often missed. Many of the tools used to measure the impact of education initiatives have not been validated and as such do not provide evidence of reliability or replicability. The GPACS-D was developed to provide a validated tool that could be used to gauge current attitudes and confidence of GPs towards dementia diagnosis and management and determine the effectiveness of dementia education in improving these parameters. Given that confidence and attitudes underpin behaviour change, application of the GPACS-D provides an evidence base to support development of educational interventions aimed at improving service delivery.

This study has shown that there are opportunities to improve the confidence and attitude of GPs both for those early in their careers and for those with clinical experience and supervisory relationships. This reinforces the need for consistent and sustained education for practitioners, particularly with regard to growing public health issues such as dementia.

The lack of confidence associated with dementia diagnosis and management may underpin the persistent use of acronyms and obfuscation when discussing dementia related issues with patients [217]. For many, there remains a resistance to using the word dementia because of a fear of causing additional anxiety for the patient [218, 219], or negatively impacting the doctor patient relationship particularly where the pathway to future support is unclear [90]. Therefore, improving the confidence and attitudes of GPs towards dementia may lead to improved disclosure processes such that a diagnosis of dementia is delivered in line with the expressed wishes of patients and their families, who seek better information and clarity. A disclosure and management plan delivered well enables the patient (and carer/family) to plan for the future, and more importantly, take an active role in the decisions that are made and emphasises the importance of early detection and disclosure [220].

Ongoing engagement and assistance highlight how important it is for GPs to have access to support services to which patients and carers can avail themselves. Increasing knowledge of available resources and support services has the potential to reduce concerns about managing dementia for both GP and carer by providing information at the time it is needed.

For GPs, educational programs may improve the capacity to inform patients and families about resources and support networks, and enhance skills around

diagnosis and management, which will underpin increased confidence leading to improved ongoing engagement with patient and carers. The GPACS-D is a validated and reliable measure of attitudes and confidence toward dementia suitable for both evaluating and measuring change in these parameters. It can assist in the development of educational initiatives by identifying elements that contribute to attitude and confidence, which can be addressed in dementia education workshops. In doing so, GPs can be provided with targeted educational interventions that potentially improve practice through confidence, knowledge, and attitude change. This thesis demonstrates that appropriately delivered educational interventions can achieve this, and while it is beyond the scope of the present study, this is likely to result in practice change.

For patients and their families, tools which help identify ways to improve diagnosis, disclosure and management of dementia will lead to better experience at a time of great stress. Confident GPs with a positive attitude towards dementia are better placed to meet their patients' needs. The delivery of a dementia diagnosis is difficult, and such tools may provide an evidence base to support education that enables GPs to do this well.

The GPACS-D is a validated tool that can be used to reliably measure the effectiveness of an educational intervention and provide a basis from which to address any deficiencies, which benefits not only GPRs but also more experienced GPs, and in doing so, delivers better outcomes for the patient and their families.

## Limitations of the research

This study was limited to survey research. While this approach provides insights into the confidence and attitudes of GPs and another means of measuring the outcomes of training and education, there are a number of limitations.

When determining the utility of the instrument in measuring changes in confidence and attitudes of GPs associated with undertaking a dementia education workshop, a pre-test post-test research design was considered the most appropriate approach given a suitable control group was not available to use as a basis for comparison. The inclusion of a control group would have been useful to compare results between those who had undertaken training and those who had not, over the same time frame and to assess the effect of the intervention and eliminate other potential explanations for results.

As with other pre-test post-test research, there is the potential for response bias emanating from a perceived need for socially desirable responses. Selfadministered questionnaires have the potential to over-rate or under-rate depending on the context in which they are administered. The self-administered and anonymous nature of the survey may have alleviated this potential bias; however, it raised the possibility of inclusion of a qualitative approach to fully interrogate responses.

This study applied the validated GPACS-D tool to address attitudes and confidence in the diagnosis and disclosure of dementia. In order to determine if an educational intervention is effective, knowledge, attitudes, confidence, *and behaviour* are among the parameters that should be evaluated. To fully explore behavioural implications of educational interventions, qualitative techniques such as focus groups, semi structured interviews, or observational research would be a useful approach to explore the impact of an intervention on practice and triangulate with survey results. Qualitative approaches would offer an effective way to explore behaviour change both through observation and interview. In other studies of practitioners' perceptions of how they disclose a dementia diagnosis, clinical practice has been found to be different from that recalled when observed [221]. Qualitative approaches may have also been useful for the development of the communication subscale.

While behaviour change is the ultimate goal of educational intervention it was beyond the scope of this study. Ideally a longitudinal approach to evaluate persistence of attitude, confidence and behaviour change would have provided a richer evidence base to assess the effectiveness of the intervention. It would have been useful to undertake a six month follow up survey to compare with results obtained directly after the workshop to establish the persistence of attitude change as well as any change in practice behaviours [129, 204].

This study recruited respondents via attendance at the educational workshop and therefore does not provide a measure from those who did not attend the intervention, or indeed those not seeking training directly. This is a major limitation as it fails to address confidence and attitudes in less accessible groups. Interestingly, data suggests that even GPs with extensive clinical experience may also require education in the management of dementia [31], particularly if they have not undertaken recent contemporary education. Therefore, sampling GPs in different contexts, such as those with no recent history of dementia training may expose prevailing attitudes in practice.

Additionally, a large proportion of GPs are also from, or work within, culturally and linguistically diverse environments which can impact their relationship with patients and attitudes towards dementia [222]. Studying GPs in different settings and contexts would be useful as a comparison of those who have, those who have

not and those who might need to undertake an educational intervention. Addressing such differences would significantly improve our understanding of practice in different contexts and provide additional insights that would have been useful for not only the development and refinement the GPACS-D survey (e.g., the inclusion of additional items and determining cultural differences), but also to review current curriculum, improve undergraduate training and determine its relevance to current clinical contexts.

Results from the 'Attitude to care' subscale were skewed with both GPRs and GP Supervisors scoring highly on this construct at baseline, indicating a possible ceiling effect. This means that there remains limited room for measurement of improvement and sensitivity to group differences. The high values at baseline and similarity of mean scores for both GPRs and Supervisors would appear to bear this out and raises the opportunity for the construct to be further re-examined in measuring the impact of the intervention as well as identifying differences between groups.

The 'Communication' subscale was eliminated from the model because of a lack of fit and redundancy, meaning that the GPACS-D omits the important question of how a GP might communicate with patients and carers about diagnosis and future management. Communication is a key contributor to the disclosure of a dementia diagnosis and the ongoing interaction with the patient and their family and is an important part of any educational intervention aimed at improving clinical practice [223]. Communication is a key skill for GPs, how they inform people of a diagnosis as well as ongoing 'conversations' surrounding prognosis and management is important to patient care [224, 225]. Communication has cognitive, affective, and behavioural components and, due to its complexity, warrants, potentially, a separate tool. It could not be described fully with reference to three variables. Potential areas of examination could include attitudes towards communication with both patient and carers (family), fears associated with disclosure (negatively impacting doctor patient relationship, increasing anxiety of the patient); the notion of 'truth' telling [226]and attitudes towards the delivery of bad news [227].

The use of other groups would also have been useful to validate the factor analysis and tackle the issue of ceiling effect observed in the *Attitude to care* subscale. Such an approach would have potentially assisted with the development of additional items that would potentially provide a more granular analysis of *Attitude to care*; for example, the extension of questions that include cognitive aspects of attitude.

## **Further research**

The survey was developed for use with GPs. A number of other professional groups have important roles in the recognition and management of dementia [48]. The GPACS-D may or may not be suitable for application to groups such as nurse practitioners and geriatricians. It would be useful to administer the survey to other health professionals who have experience of dementia to assess its applicability and utility with these groups.

Opportunities exist to apply a framework such as the Consensus based standards for the Selection of health Measurement Instruments (COSMIN) as an additional process to formally evaluate the utility of this tool to document its measurement properties according to agreed standards [228].

Communication is a key contributor to the disclosure of dementia diagnosis and the ongoing interaction with the patient and their family. Determining the effectiveness of education in improving this warrants further investigation.

Ultimately, the most important outcome of education is improving practice in dementia. Continuing education for GPs is crucial to continual improvement in clinical practice and health services, which benefits the patient, family members and carers. It would be beneficial therefore to conduct further research in order to understand the impact of education on clinical practice for both GPs and GPRs and to evaluate and quantify the exposure of registrars to opportunities to hone their skills in the recognition, diagnosis, and management of dementia.

To date, the survey has been taken up by a number of research groups in international settings. The utility in these settings is the subject of current research and findings are anticipated to emerge in the near future.

## Conclusion

This research had two main goals: to develop a valid and reliable tool to measure GP attitudes and confidence towards dementia and use it to measure the impact of a dementia educational intervention. The GPACS-D was developed after a rigorous process of tool development and is a valid and reliable tool to gauge the effectiveness of an educational intervention aimed at improving a GP's response to diagnosing and managing dementia. Through examining confidence and attitudes toward dementia of GPs, education can be designed which addresses deficiencies in these areas.

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Appendix 1: GPACS-D



## General Practitioners' Attitudes and Confidence Scale - Dementia (GPACS-D)

Please read the following statements carefully. Once you have read each statement, please circle the number on the scale that corresponds with your answer, where 1 is 'Strongly Disagree' 3 is 'Neither Agree or Disagree' and 5 is 'Strongly Agree'.

Subscale Factor		Strongly Disagree			Strongly Agree	
AC (0.72)	1. Much can be done to improve the quality of life for people with dementia.	1	2	3	4	5
E (0.406)	2. Managing dementia is more often frustrating than rewarding. (reverse score)	1	2	3	4	5
AC (0.132)	3. The early detection of dementia benefits the patient.	1	2	3	4	5
AC (0.318)	4. It is important for relative/family carers of people with dementia to seek external support (e.g. counselling/support groups).	1	2	3	4	5
AC (0.210)	5. Relatives/family carers of patients with dementia should be encouraged to contact Alzheimer's Australia.	1	2	3	4	5
AC (0.115)	<ol> <li>GPs are in the best position to help relatives/carers with organising care for someone with dementia.</li> </ol>	1	2	3	4	5
E (0.108)	7. I fear communicating a diagnosis of dementia will damage the doctor patient relationship. (reverse score)	1	2	3	4	5
E (0.485)	8. I prefer treating patients with other chronic diseases such as diabetes mellitus or hypertension. (reverse score)	1	2	3	4	5

Subscale Factor		Strongly Disagree			Strongly Agree	
AC (0.150)	9. Patients with dementia should be informed early so they can plan for the future.	1	2	3	4	5
CCA (0.073)	10. I feel frustrated because I do not know how to effectively treat people with dementia. (reverse score)	1	2	3	4	5
CCA (0.101)	11. I feel confident in my ability to discuss legal issues associated with a diagnosis of dementia.	1	2	3	4	5
CCA (0.151)	12. I feel confident in my ability to diagnose dementia.	1	2	3	4	5
CCA (0.298)	13. I feel confident in my ability to provide appropriate medical care for a person with dementia.	1	2	3	4	5
CCA (0.288)	14. I feel confident in my ability to provide advice about managing dementia related symptoms.	1	2	3	4	5
CCA (0.095)	15. I feel confident in my knowledge of local resources to assist families/carers caring for a person with dementia.	1	2	3	4	5

CCA = Confidence in clinical ability AC= Attitude to care E=Engagement

Scoring: for each subscale, the simplest approach is to sum the scores (taking note of the reverse scored items) and divide by the number of items in the subscale to give an average score out of 5 for each of the three subscales and total score.

Alternately if the intention is to exploit the psychometric properties of the scale, then scores can be weighted. Factor scores are shown above for each item. Item score should be multiplied by the given factor score prior to summing for each of the subscales and total score.