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# ASSESSING COGNITIVE FUNCTIONING IN OLDER ADULTS AND ITS

# **RELATIONSHIP TO QUALITY OF LIFE**

A thesis presented in partial fulfilment of the requirements for the degree of

Doctorate

in

Clinical Psychology

at Massey University, Wellington,

New Zealand

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#### ABSTRACT

Cognitive impairment of any magnitude carries an undetermined societal and individual cost. The desire to accurately predict cognitive decline at an early stage is sought-after as robust cognitive health and function in later life is desirable. Knowing who is at risk and what those risks may be is imperative for targeting interventions to those in need. The lack of nationally representative information regarding cognitive functioning means that there is little information about base rates of cognitive functioning. This represents a problem in terms of gauging the incidence of cognitive impairment and difficulties related to planning for social and health expenditure for the ageing population. This thesis explores the validity and reliability of the Addenbrooke's Cognitive Examination-Revised and develops New Zealand norms for the measure using data from the New Zealand Longitudinal Study of Ageing. These demographically stratified norms will help to determine those people who may be more vulnerable to a dementing process. The information is applied in the context of examining the impact of cognitive functioning on quality of life; an important concept to consider in research.

In article one, a pilot study of the use of the Addenbrooke's Cognitive Examination-Revised (ACE-R) with older community dwelling adults, the utility of the measure was supported. In article two, the ACE-R was integrated into a nationwide longitudinal study of older adults. Stratified demographic norms were created. This is the first known nationally representative New Zealand study to provide evidence of the impact of age, gender and ethnicity on measures of cognitive functioning. In article three this information was applied in the study of the relationship between cognitive functioning and quality of life. Results suggested that cognitive functioning has a small significant association with quality of life in older age and a much larger association in those who display cognitive functioning difficulties. This research adds to the research base in New Zealand by providing representative norms from which older adults can be compared in a meaningful and specific way.

#### ACKNOWLEDGEMENTS

It is with great excitement that I write this page, as it means that the thesis is ready to submit! This process has not been easy - many late nights, worrying, procrastination... Now that it is all written and done, there is a hope that this research will be beneficial to others in some way to help promote quality in life. There are a number of people I would like to thank who helped me through this process. Thank you to my participants whose willingness to help and openness to share was humbling. To my supervisors, Associate Professor Fiona Alpass and Professor Janet Leathem, your guiding support through this process provided direction, discussion and discourse, thank you. Thanks to the New Zealand Longitudinal Study of Ageing, (NZLSA; Massey University and the Family Centre) for allowing me the opportunity to work in this special area and for providing such a rich and varied database to work with. A huge thanks also to my family and friends for their patience, unconditional support and unrelenting questions about when I will be finished which kept me grounded and motivated. Also thanks to some great friends: Lyn, Veena and Lucia, for the distracting conversations that added humour and enrichment to many years of study. To those at Harakeke Club, (Presbyterian Support Elder Care) thank-you; introducing and encouraging my interest in working with older adults helped me to become the person I am today.

#### Contribution of author to project

The author was responsible for most aspects of this research, including the formulation of research questions and data collection for the pilot study (Article 1), data analysis, interpretation and write up of the papers (Article 2 and 3). Data for Article 2 and 3 was collected and collated by the NZLSA research team, principle investigators – Associate Professor Fiona Alpass, Professor Christine Stephens, Mr Charles Waldegrave and Dr Peter King.

## Candidate's Declaration

I, Lauren Callow, candidate for the degree of Doctor of Clinical Psychology at Massey University Wellington, do hereby certify that:

- The papers and thesis contained herein comprise entirely my original work towards the degree,
- 2. This work has not been submitted to any other university or institution for a higher degree,
- 3. The thesis including papers is less than 65,000 words in length, excluding tables, references and appendices,
- Ethics approval for the research was obtained by the Massey University Human Ethics Committee: Southern B, Application 10/23.

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Lauren Callow

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#### **CHAPTER ONE: OVERVIEW**

This thesis came about from an inherent interest in the well-being of older adults and a desire to ensure that their needs are met as the older population outgrows the rest of the population. Having worked with older people and their families who were coping with progressive cognitive difficulties, I saw people struggling to make sense of the world because of a damaged mind. This damage affected their thinking, speech and behaviours and was unique to the individual in the way that it impacted, challenged and progressed. This led me to consider the influences on these factors, about what could be done to minimise the chances of this assault, maintaining a good quality of life despite a debilitating disease processes. These experiences formed the basis of my research into older adults and cognition.

The implications of cognitive functioning, and its changes with increasing age, are complex and require more research to aid our understanding. Conceptualizing and measuring cognitive functioning is critical for research with older populations so that this complexity can become better understood. The aim of this research is to identify the relationship between cognitive functioning and older adults' quality of life by providing a baseline of cognitive functioning. Over time the rate and severity of cognitive change and the factors that may impact this process can be analysed, and the unique contribution this may have to quality of life can be investigated.

New Zealand is in the midst of a population transition. The convergence of three demographic trends have led to an increased older population in New Zealand that follows similar international trends; people are living longer due to improvements in health and welfare; fertility rates have declined and the 'baby-boom' generation is now approaching retirement age. According to the 2006 New Zealand Census of Population and Dwellings, there were 495,600 New Zealand residents who were aged 65 years and over, up 45,200 on the 2001 Census (Statistics New Zealand, 2006). This represented the largest between census growths for this group in our recorded demographic history. Over the last half a century, the growth of the 65+ group has

consistently outpaced the growth of total New Zealand population. As a consequence, they now make up one in eight (12.3%) of all New Zealanders, compared with one in 12 (8.5%) in the early 1970s.

These demographic changes create challenges for supporting the older population as the current problems experienced by the aged care sector are set to explode in future decades, (e.g., meeting the increased physical health care needs). The health of older people is becoming a global priority. The United States Congress designated the 1990's as the 'decade of the brain' with a huge increase in funding for research into ageing and ameliorating its effects. The National Institute of Health has increased its budget for ageing research by three times to support research into many aspects of ageing (National Institute on Aging & National Institutes of Health, 2007). This includes research into: the biology of ageing, psychological, cultural, social and economic factors that affect ageing, the maintenance of health and functioning, and the differences between normal age-related changes in functioning and pathological disease associated with ageing (National Institutes of Health, 2007). In New Zealand the government has followed suit and pursued the priority through implementation of policies and initiatives that are trying to provide: better services, (and more of them) to support older people to remain in their homes ("ageing in place"), better wrap-around care for older people and stronger monitoring of the aged residential care sector (Ministry of Health, 2012b).

A notable policy objective for the current government is to support older people to live longer in the community as this is the more cost-effective option compared to long term care and also contributes to greater wellbeing, independence and participation for older adults (Butler, Forette, & Greengross, 2004). A large barrier to independent living in the community is impaired cognitive functioning (Perry & Hodges, 2000). Cognitive functioning involves a system of abilities that can be grouped into different categories including; memory, attention, language, executive function, perception and spatial ability. Each system involves processes that integrate and organize information from the environment and allow a person to process, perceive, or comprehend ideas and thoughts and take cognitively consistent action.

Cognitive functioning is a significant indicator of overall health and many skills can become disrupted with the progression of cognitive impairment, especially core skills like reasoning, memory, orientation, calculation and language. Disruption of core cognitive skills can cause difficulties in instrumental activities of daily life, (paying bills, medical regimes, planning activities) and activities of daily life (dressing, bathing) (Christensen, 2001). Cognitive functioning difficulties also play a pivotal role in relation to health care utilization among older adults with increased rates of hospitalization, institutionalization and death (Herzog & Wallace, 1997). Furthermore, cognitive impairments can impact financially through effecting work, decision making and retirement (Lachman & Spiro, 2002), These factors associated with declines in cognitive functioning are primary risk factors for entering a residential setting (Perry & Hodges, 2000).

Due to the wide-ranging and often severely limiting effects of cognitive functioning, it is a feared consequence of ageing. An American study found that people fear "losing our mental capacity" twice as much as the fear of diminished physical ability and around 60% of people were very or somewhat worried about memory loss (Cutler, Whitelaw, & Beattie, 2002). It is not a baseless fear; memory-related difficulties are a widely reported complaint associated with ageing with at least 10% of persons older than 65 years and 50% of those older than 85 years having some form of cognitive impairment, ranging from mild deficits to severe dementia (Jorm & Jolley, 1998). Studies have shown that dementia, (a disease on the severe clinical end of the cognitive functioning spectrum), is the fourth leading cause of death among the population aged 65 years and over and is associated with an earlier need for residential care and health resources (Alzheimers New Zealand, 2008). A United States study found that dementia was the most feared disease; due to a slow process of losing a sense of self and those you love, whilst becoming dependent on others (Special Committee on Aging United States Senate, 2011). Because of this, it

becomes increasingly important to: understand age-related changes in cognitive functioning, and have accurate estimates of the prevalence of cognitive impairments in order to help provide accurate education to those who are concerned.

Despite the increasing numbers of older people, very few studies look at the prevalence of cognitive impairment, particularly in New Zealand. While considerable information exists regarding the socio-demographic characteristics of the older population, e.g., gender, housing, employment, (Ogden & McFarlane-Nathan, 1997a; Statistics New Zealand, 2009), information regarding the mental, (including cognitive) health of this cohort is limited. For example, in a national snapshot about the health of New Zealanders (n= 12,000 adults aged 15 – 75+), selected randomly from throughout New Zealand, (Ministry of Health, 2012a), there was no mention of cognitive health. Neither was there mention in a New Zealand Mental Health Survey (n=12,992 aged 16 years and over), (Te Rau Hinengaro, Oakley Browne, Wells, & Scott, 2006). In that report it was noted that the survey does not provide estimates of rates of dementia and associated cognitive impairment in older people due to not sampling people within institutions or those with low-prevalence disorders. In a further national study, focusing on Māori participants it was stated that "dementia prevalence is also important however this could not be included in this chart book due to the lack of reliable data." (Ministry of Health, 2011, p. 51).

Failure to recognise cognitive impairment reduces the time for advance planning, (making lifestyle changes or starting medication) and causes trauma and uncertainty for people with difficulties, their families and their workplaces. Accurate assessment and education can help distinguish dementia from reversible forms of cognitive impairment, (e.g., depression) as well as improve public awareness about normal and abnormal cognitive decline. Additionally, early interventions such as social enrichment activities, home based treatment, risk reduction, community based support services and self-management can help delay entry into residential care and reduce economic and social costs that are associated with cognitive impairment (Alzheimers New Zealand, 2008; Ball et al., 2002; Woods, Thorgrimsen, Spector, Royan, & Orrell, 2006). For

example, preventative therapy (e.g., medication), delays the onset of Alzheimer's Disease (AD) symptoms by 3.5 years and early detection and treatment reduces progression by at least 2.8 years; giving the affected person an average of six more years of good quality of life and extending life expectancy (American Academy of Neurology, 2004).

New Zealand studies have not measured cognitive functioning at a population based level (Carroll, 1993; Statistics New Zealand, 2006). From the longitudinal United States Health and Retirement Study (HRS), initial estimates suggest that 10% of the United States population aged 70 years and over had moderate to severe impairment of cognitive function (National Institute on Aging & National Institutes of Health, 2007). Prevalence and projection rates of dementia in New Zealand are varied, with those aged over 65 ranging from 1% to 40%, depending on the age group studied (Campbell, McCosh, & Reinken, 1983). This study is dated and these estimates need revision and clarification. In other studies of dementia in developed countries, prevalence rates double exponentially every 5.1 years between ages 60-90, and fall away after age 95 (Special Committee on Aging United States Senate, 2011). This New Zealand data does not include the more subtle cognitive impairments that are likely to increase in prevalence with the ageing trends of our population. To the author's knowledge there have been no population based studies in New Zealand investigating cognitive functioning in non-dementing older adults. The exclusion of rates of cognitive impairment and what is 'normal' cognitive functioning represents a significant gap in the health literature. The lack of base rates of cognitive function makes it difficult to derive reliable and valid national estimates of impairment, develop explanatory models of cognitive changes and predict the needs of this unique growing population for policy and care implementation.

Often 'normal' populations are used as a reference point of comparison to assess cognitive decline in individuals, with normal being the absence of any known pathology or disease process (Powell & Whitlia, 1994). However, there is no definitive conceptualisation in the literature on cognitive ageing nor guidelines as to what normal ageing is. Given theorists' confusion about the distinction between cognitive decline that may be a result of normal ageing and the development of dementia, it is understandable if the general public may also be confused. A qualitative study of older people's perceptions around cognitive function showed that older people had little knowledge about normal and abnormal cognitive functioning (Corner & Bond, 2004). Participants linked memory loss to the inevitable development of senile dementia, there was uncertainty about the causes of dementia and what was 'normal', a fear of developing dementia, (due to perceived loss of independence, control, identity and dignity) and a pervasive sense that there was little to be done to prevent the development of dementia (Corner & Bond, 2004). The confusion demonstrates the importance of providing ways to define the boundaries that separate normal and abnormal cognitive ageing; an ongoing challenge to researchers.

One of the difficulties when researching cognitive change within New Zealand's ageing population is a lack of research about *normative* cognitive change. Norms of cognitive tests tend to be based on North American samples and are often used as a benchmark for monitoring 'normal and 'abnormal'. These norms do not incorporate the unique diversity within New Zealand which therefore creates challenges in accurately assessing cognitive difficulties and restricts the ability to provide opportunities for early interventions. There is a need for a reference or standardization group that is adequately matched or balanced with the individual under assessment. This thesis will address this gap in the literature by providing normative data for older New Zealanders with a measure of cognitive functioning.

This information will be applied in the context of investigating the role that cognitive functioning has with quality of life. Quality of life is becoming an important concept within ageing populations as governments attempt to promote not just the prolonging of life but also the quality. For example, in New Zealand the positive ageing strategy encourages independence (Ministry of Social Development, 2001), a specific factor known to improve quality of life in older people (Keeling, 1999). Cognitive functioning has been noted as important in models of quality of life due to the impact it can have on what information we attend to and recall. (Lawton & Powell,

1991). Even though cognitive functioning has the potential to affect quality of life scores, particularly in older people where cognitive decline can be a common occurrence, it is not routinely assessed in quality of life research. Given this, there is a need to investigate the role that cognition plays in quality of life, using appropriate and sensitive measures. Many studies looking at ageing and quality of life do not use appropriate quality of life measures, neglecting to take into account the changes that occur with ageing (Wiggins, Netuveli, Hyde, Higgs, & Blane, 2008), or use single domain measures that neglect to account for the multi-dimensional nature of quality of life (Cella, 1994). This thesis addresses these issues by using a valid cognitive assessment tool and a variety of quality of life measures which encapsulate the effects of ageing and the breadth of the concept.

#### Summary

Given the increasing aged population, the incidence of cognitive functioning difficulties will increase. The difficulty distinguishing between normal and abnormal cognitive functioning makes cognitive decline a huge fear of older adults and without tools to help distinguish between normal and abnormal functioning, early interventions, education and accurate policy changes may not occur. There is a need for accurate New Zealand specific normative data on cognitive functioning so that older adults have a baseline from which to be compared. Given the importance of maintaining a quality life through the life course, the role that cognitive functioning has on quality of life also needs to be researched. This information affords opportunities for continued monitoring and understanding of what may be important for early intervention. Understanding the factors that are connected with individual differences in cognitive ageing and quality of life will enhance the accuracy of these interventions.

This thesis will contribute to the research surrounding the measurement of cognitive functioning in New Zealand and its application by:

- Undertaking a pilot study assessing the validity of the Addenbrooke's Cognitive Examination Revised cognitive screening measure in New Zealand community dwelling older adults
- Providing normative data, stratified by demographic variables, for community based levels of cognitive functioning and a baseline from which cognitive change can be measured over time in subsequent studies.
- Investigating the role cognitive functioning may play in the quality of life experience in older age.

### **Thesis Outline**

This thesis is presented as a thesis by publication, and thus there are manuscripts prepared for publication embedded within it. This format necessitates some overlap of content between the chapter introductions and the information presented in the articles. The second chapter in this study begins with a discussion of cognitive functioning and the theories that explain the process of cognitive change in older age. Following this, cognitive changes that occur, and the mechanism of change, are explored within the different cognitive domains. Chapter three focuses on how cognitive functioning is measured in different research studies and what the potential pros and cons of different measures and approaches are. A manuscript, to be submitted for publication, presents a pilot study investigating the utility of using the Addenbrooke's Cognitive Examination-Revised (ACE-R) as a measure of cognitive functioning in older adults. Chapter four then explores the individual variation in cognitive ageing across a number of socio-demographic variables. A manuscript, to be submitted for publication, shows the influence of some of these demographic factors on cognitive functioning (using the ACE-R) and provides normative data for use nationwide. The data for this article is sourced from the New Zealand Longitudinal Study of Ageing which is a longitudinal study into the factors that influence quality of life in older age. The current research adds to the longitudinal study through the incorporation of a cognitive functioning assessment which can then be routinely used over time. Chapter five examines how cognitive functioning may be associated with older adults' ratings of their quality of life. A

manuscript, to be submitted for publication, presents the results of a study that looks at the relationship between quality of life and cognitive functioning in older adults. Finally, Chapter 6 is a discussion of the overall research findings and how they relate to theoretical perspectives and previous research and concludes with the limitations of the current research and direction for future research.

### CHAPTER TWO: COGNITIVE CHANGES THAT OCCUR WITH NORMAL AGEING

#### Theories of cognitive change

Cognitive ageing theories are important to help understand and explain cognitive change so that theoretically informed interventions can be developed to improve health care in older populations. There are many theories proposed to explain how cognitive functions change with age and why some decline at a faster rate than others. Difficulties arise as there is vast heterogeneity and complexity within cognitive ageing in older adults. The current knowledge base is not extensive enough to pinpoint exactly why some people and not others develop cognitive functioning difficulties, why some domains are spared, when domains start declining and at what rate. In addition, there are a large number of factors that can potentially impact cognitive functioning such as biological, socio-cultural factors, disease, education and social support. The following section will summarise key theoretical perspectives.

#### **Continuum Approach**

Theories of normal cognitive ageing often propose that changes in cognitive function are part of the life span and not because of any abnormal disease process (Small, Mobly, Laukka, Jones, & Baeckmann, 2003). A non-pathological decline in cognitive functioning is often stated as the beginning of a downward trajectory into mild cognitive impairment and eventually dementia (Brayne, Best, Muir, Richards, & Gill, 1997). In a study which attempted to differentiate between normal and pathological cognitive declines (Hill, Storandt, & LaBarge, 1992), a battery of neuropsychological tests was administered to participants who had already been classified as either 'normal' or with mild Alzheimer's Disease (AD). Results suggested that normal participants could be differentiated from those with mild AD based on their scores on the memory, speeded visual-motor performance and object naming subtests. However, the authors also found considerable overlap between the scores of the groups so that no cut-off point could be generated that allowed for accurate discrimination (Hill et al., 1992). This led to the conclusion that normal cognitive ageing and mild AD were not separate entities. In support of this, a noted

Oxford physician and gerontologist J. Grimley Evans said, "In fact, to draw a distinction between disease and normal ageing is an attempt to separate the undefined from the undefinable", (pg. 141 as cited by Powell & Whitlia, 1994). Brayne (1997) suggested that there is very little evidence to support the view that dementia (particularly of the Alzheimer's type) is distinct from the normal ageing process. He argues that the changes in brain function found in normal ageing ('benign senescent forgetfulness'), and Alzheimer's Disease (AD) can be seen as a continuum, which may reflect a single underlying process, where the two cognitive states are distributed uni-modally from normal to demented (Brayne et al., 1997).

The idea that AD may be an acceleration of normal ageing comes from research that suggests pathological changes assumed to be necessary for AD are present, though to a lesser extent, in normal older people. For example, those who do not develop dementia can also show senile plaques and neurofibrillary tangles, common signs of a dementing process (Carlesimo et al., 1998; Price, Davis, & Morris, 1991). In another study comparing adults with AD with healthy adults of varying ages it was found that there was progressive decline passing from young to elderly normal adults, with those with AD comparable or worse than very old subjects (Carlesimo et al., 1998). The authors suggested that many aspects of memory function that are deficient in patients with AD (particularly in the early part of the disease), decline to a lesser extent in normal elderly persons, suggesting a continuum exists between functional impairment of some neural networks in ageing and dementia. However, not everyone shows cognitive declines as they age with less than 1% of people with age-associated cognitive impairments developing dementia and about 50% of people with Mild Cognitive Impairment (MCI) developing dementia within three years of diagnosis (Ringdal & Ringdal, 1993).

This model provides a useful framework for understanding the 'shades' of cognitive impairment that may be encountered in people who do not meet diagnosis criteria for dementia. However, the theory needs to be supplemented to explain the processes and unique contributors toward the variability, rate, and severity of cognitive change along the continuum.

#### **Neuro-pathological Evidence**

The biology of cognitive change with ageing is not well understood and the research into cognitive and brain changes across the lifespan is fairly new. The ageing of the brain and subsequent pathology resulting from age are assumed to underlie many of the cognitive deficits; as several studies have shown significant correlations between structure and function (Jones, Rapport, Hanks, Lichtenberg, & Telmet, 2003; Reuter-Lorenz, 2000). There are changes in brain regions in the frontal and medial temporal lobes, (and the networks in which they operate) that change in older age and lead to declines in encoding, retrieval of memories, working memory and other cognitive functions. Cross-sectional studies have shown substantial age differences in ventricular, cerebrospinal, brain, hippocampal, frontal and temporal lobe volumes (Jones et al., 2003). Volume decreases due to cell loss and shrinkage (atrophy) have been found to occur more with increasing age with an average rate of decline of 0.9% to 1.5%, and frontal lobes showing the steepest rate of atrophy (Resnick, 2003), The parietal lobes also show a steep decline with an annual rate of atrophy between 0.34% and 0.9% (Resnick, Pham, Kraut, Zonderman, & Davatzikos, 2003). Different rates of atrophy also exist within sub-cortical areas, e.g., hippocampus, corpus callosum and the cerebellum have greater rates of atrophy with age than other structures (Dennis & Cabeza, 2008).

Neuro-imaging studies suggest significant age related differences with white and grey matter decline. White matter loss occurs throughout the brain with ageing and is more extensive than grey matter loss (Dennis & Cabeza, 2008). White matter has been linked to performance on executive functioning tasks (Dennis & Cabeza, 2008), measures of processing speed, reasoning and memory performance (Persson et al., 2006b).

Less blood supply to the brain can occur through artery walls losing elastin which makes them less efficient (Reuter-Lorenz, 2000). The changes that occur in the resting blood flow and metabolism have been linked to declines in encoding and retrieval of explicit memory, contextual memory, working memory and inhibition (Reuter-Lorenz, 2000).

The boundary between normal and pathological cognitive ageing is hard to pin point as they tend to overlap in transition because neuro-pathology can begin before any cognitive changes are visible (Thorgrimsen et al., 2003). In addition, some people who are ageing 'normally' at one point in time may later develop dementia, suggesting that their earlier normal functioning was compromised by pre-clinical signs of dementia (Padilla, Mishel, & Grant, 1992).

The neuro-pathological research base is a good step towards showing the changes in the ageing brain and the associated impact on rate and severity of specific cognitive domain impairments. Unfortunately the research does not suggest who is more likely to be affected by these changes.

#### **Summary**

Theories of cognitive ageing have a difficult task of explaining the what, why, how and when of cognitive ageing. Almost all memory and cognitive variables are hypothesized to reflect a mixture of different processes, but the extent to which processes are contributing to age differences is unknown. No one theory answers all the questions and as such there are different theories suggesting a range of possible explanations for cognitive ageing. It is likely that the above explanations are interdependent. The next section will explore the 'what' of cognitive functioning, framed within the above 'why' explanations.

### Cognitive domains and the impact of ageing

In addition to the theories presented above, there are cognitive domains that are also implicated in theories of cognitive ageing. The main cognitive domains and aspects of theory that relate to them are presented below.

### **Processing Speed**

A prolific researcher in the cognitive ageing area, Timothy Salthouse, proposes that the agerelated decline in learning and memory is primarily a function of age-related decline in speed and efficiency of information processing, a cognitive domain (Salthouse, 1996). Salthouse suggests that cognitive performance is impaired when processing is slow because important operations cannot be successfully executed. Christensen, (2001) showed in a meta-analysis study that "cognitive speed drops by approximately 20% at age 40 and by 40-60% at 80" (p. 769). Supporting this, longitudinal research consistently finds that processing speed significantly deteriorates with advancing age (Albert, Blackler, Moss, Tanzi, & McArdle, 2007; Centre for Ageing Studies, 2006; Hultsch, Hertzog, Small, McDonald-Miszczak, & Dixon, 1992) and accounts for a large amount of variance in age-related cognitive tasks (Salthouse, 1996). Processing speed is linked to cellular and structural changes in the brain and a decrease of volume in the frontal cortex (Persson et al., 2006a). Furthermore, ageing is associated with a decrease in the production of neurotransmitters (the brain's messengers) due to loss of cells and receptor cells and an increase in specific proteins that interfere with the brain's functioning, as well as demyelination of neurons, which could result in slowing of information processing (Wiggins et al., 2008). This suggests a global model of age-related changes causing cognitive skills to decline at similar rates because they are strongly dependent on the maximum speed with which we can process information. Overall, reduced information processing speed appears to reflect a genuine slowing of mental processing within the central nervous system which has a subsequent effect on all other cognitive functions.

#### Attention and Effortful/Automatic Recall

Attention, has a limited capacity where only some processing activity can take place at a time. Attentional difficulties can impact on an older person's ability to function adequately and independently because some form of attention is involved in almost all of the cognitive domains. Attentional tasks that require dividing or switching attention among tasks or input, (e.g., driving), are impaired more in older adults than younger people, particularly when the attentional demands of the task are high (Gabriel & Bowling, 2004). Older adults also appear to be less able to appropriately allocate resources when given instructions about priority (Veenhoven, 2000). These findings are often explained in terms of declining processing resources associated with normal ageing. For example, it has been suggested that selective attention remains intact in older adults, but they are slower than younger adults in responding to targets (Verhaeghen & Salthouse, 1997). Therefore deficits found in selective attention tasks may be suggestive of a more general slowing of information processing rather than selective attention deficits per se.

An important theoretical distinction that may inform our understanding of why older adults do well on some cognitive tasks but not others, involves the distinction between effortful and automatic processes. Craik, (2000) summarised some key aspects of memory loss in older adults noting that difficulties are most common in situations requiring large amounts of cognitive operations that are neither habitual nor well supported in the environmental context but that must be initiated and performed in a conscious and effortful manner. In this regard anything that requires effortful recall or effortful encoding may be more difficult to remember. Craik attributed this to a depletion of attentional resources involving a reduction in mental energy, (the reservoir of psychological energy that is available to perform a given task at a given time) and more difficulty storing and manipulating information in the working memory. Effortful processing requires a substantial mental energy and occurs at times when the person must deliberately search for information from memory, actively manipulate information or consciously attempt to solve a problem. In contrast, automatic processing requires little or no mental capacity to perform and may develop as a result of repeated experience. In general, the less practised, the more difficult or complex the tasks are and the larger the negative age difference (Craik, 2000; Salthouse, 2000). This is supported with research that shows that with tasks involving high attentional demands older people show impairments, whereas tasks involving little attention, (e.g., automatic) are largely intact, (Park, 2000; The WHOQOL Group, 1994; Ware & Sherbourne, 1992). This theory of how attention is impaired in older adults is more descriptive than explanatory and lacks a firm definition of 'attentional resources'; however, it is consistent with Salthouse's information processing theory and the idea of familiarity or procedural knowledge tasks being easier to perform in older age (Christensen, 2001).

### Memory

Declining memory is one of the most widespread complaints about ageing (Oakley Browne et al., 2006). Memory is not a unitary construct and changes can occur in different aspects of the memory system.

*Working memory.* Working memory is a complex combination of attention, concentration and short-term memory. Models of working memory suggest that it is a limited capacity system which allows us to retain information for a few seconds and involves the active reorganization and manipulation of information that needs to be kept in mind (Woods et al., 2006). Working memory ability is highly influenced by age (Selai, 2001) and has been hypothesized as the fundamental source of age-related deficits in many cognitive tasks including long term memory, language, problem solving and decision making (Craik, 2000; Evans et al., 1989; Selai, 2001). Difficulties with working memory can be seen in problems with concentration and performing new tasks that involve multiple instructions. Age-related working memory decline is shown in many cognitive tests including letter number sequence tasks, backward digit span and sentence span (Blackler et al., 2007; Tucker-Drob & Salthouse, 2008).

*Long term memory (LTM).* This is a memory storage system that requires retrieval of information that is no longer present or being actively maintained. Long term memory comprises of declarative (autobiographical/episodic and semantic) and procedural types of memory (doing tasks). Everyday memory lapses are likely to involve poor encoding due to the reduced use of effortful encoding strategies (Craik, 2000). It is also possible that during input, encoding new information may be done less meaningfully and with less elaboration so that the memory becomes

less distinctive and difficult to retrieve (Bowling & Stenner, 2010). For example, storage or consolidation of memories may become more difficult as this depends on the temporal lobe and the hippocampus areas which show age-related changes (Reuter-Lorenz, 2000). Furthermore, older people may attend to salient, focal information and fail to take in peripheral detail or may fail to integrate contextual aspects of an experience with central content (Craik, 2000). It may also be that noticing and integrating various aspects of an experience involve divided attention and require working memory which can be affected by ageing.

Episodic memory is a declarative memory system for personal experienced events and comprises of both anterograde (newly encountered information) and retrograde, (past events) components. Episodic declarative memory appears to be the form of memory most affected by normal ageing and is often mentioned as a concern in older adults (Evans et al., 1989; The WHOQOL Group, 1994). Older adults have more difficulty remembering when and where they experienced an event or learned a fact (Craik, 2000) and tend to report fewer details surrounding an event (Daatland, 2005). However, differences are reduced when the recall is in context, is a particularly salient event (Craik, 2000) or has a strong emotional component or personal investment (Daatland, 2005).

Semantic memory refers to the general store of conceptual and factual knowledge, which is not related to any specific memory. This information is not tied to space, time of learning and is declarative and explicit in nature. Semantic memory is less affected by ageing than episodic memory but it is still not completely spared. There are often retrieval failures such as trouble recalling names of items whose names were previously known and although older adults often show better semantic knowledge than younger people, it may take longer to retrieve that information (Lawton, Winter, Kleban, & Ruckdeschel, 1999b). *Short term memory.* The term "short term" memory is applied, to a number of different memory problems, but has no convincing anatomical or psychological correlate (Reuter-Lorenz, 2000). Short term memory involves simple maintenance of information over a short period of time. Assessment of memory with tests that provide multiple learning trials suggest that normal ageing does not affect retention but rather effects encoding and efficient retrieval (Elderkin-Thompson, Mintz, Haroon, Lavretsky, & Kumar, 2007).

*Procedural memory.* This refers to the ability to learn behavioural and cognitive skills that are used at an automatic or unconscious level. It is non-declarative but can be explicit or implicit, (e.g., playing the piano or riding a bike). These high skill activities are more slowly acquired through repeat practice and tend to be quite automatic as they do not involve conscious recollection of initial learning (Craik, 2000). Difficulties of procedural memory become evident when somebody shows difficulty with previously learnt skills or in learning new skills but is generally spared in older age unless there is a more severe dementing process occurring (Glisky, 2007).

## Perception

Perception is a way of gaining awareness or understanding of stimuli by organizing and interpreting sensory information. Older age is associated with reduced perceptual ability (Cullum et al., 2000). Sensory difficulties: hearing, visual, tactile, can lead to perceptual difficulties, since the latter depends on the former. Perceptual difficulties can also occur in relation to brain changes, unrelated to sensory difficulties. Perceptual difficulties can impact older adults immensely, for example they could experience social isolation due to hearing loss, or lose the ability to drive through visual difficulties. As a result of perceptual difficulties it is possible that older adults perform cognitive tasks less efficiently, (e.g., slowed comprehension due to hearing loss or trying to make sense of words said at speed (Cullum et al., 2000).

#### **Visual-Spatial**

Visual-spatial skills allow recognition of objects and their location or orientation in space, identifying shapes and co-ordinating motor movements with that information, (e.g., drawing). Longitudinal studies that implement tests of visual-spatial skills (e.g., the Block Design, from the Wechsler Adult Intelligence Test – IV) have shown notable within-person deterioration from the age of 60 (Rönnlund & Nilsson, 2006).

### Speech and Language

The speech and language domain refers to our ability to recognise and process words, make word associations and respond verbally to others. Speech and language is heavily influenced by the frontal lobe which controls our expressive language, assigns meaning to the words we choose and is involved with word associations. The temporal lobes are involved with auditory processing of words and the occipital lobe for visual processing of words. Speech and language skills are largely intact in older adults. Older adults tend to show skilled conversations with awide vocabulary and narratives, however processing time may be slower than in younger people (Glisky, 2007). Deficits that occur under difficult processing conditions (e.g., speed) may be attributable to sensory loss or working memory limitations rather than language difficulties (Glisky, 2007).

#### **Executive Function**

Executive function is an adaptive balance of, maintaining and shifting cognitive or behavioural responses to environmental demands. It enables a person to engage successfully in independent, purposeful, self-serving behaviour. It involves higher cognitive function, (primarily located in the frontal lobe) such as long term goal-directed behaviour (rather than reflexive automated action), and as such involves: problem solving, decision making, initiation, self-monitoring, mental flexibility, response inhibition, motivation, abstract thinking, planning, making judgements, reasoning andorganizing. Executive functioning plays a key role in almost all cognition. For example, allocating attentional resources to stimuli, inhibiting distracting or irrelevant information

in episodic memory, formulating strategies for encoding and retrieval and deciding goal-directed activities are all part of executive functioning.

Decision making is a critical executive function cognitive task which creates demands on processing resources and can be assisted by relevant knowledge or expertise in problem solving. Compared to younger adults, older adults tend to come to the same decisions, (based on vignettes) as younger people but they get to that decision in different ways and more slowly. Older adults tend to rely on prior knowledge and less on new information. Thus when a difficulty arises in making decisions it is often due to episodic memory decline or loss of memory for details (Glisky, 2007). When executive function is not explicitly tested, problems in this domain may be apparent in cognitive testing by noticing less ability to initiate activity, absent motivation and deficits in planning and carrying out an activity which requires goal-directed behaviours. Even with considerable cognitive loss, as long as executive function is intact a person can sustain a fairly independent productive life.

### Summary

Not all cognitive abilities decline with age, some are spared while others decline at variable speeds. Ageing is associated with more difficulty in processing of information quickly, ignoring irrelevant information or thoughts, learning new skills and inhibiting dominant responses (Selai, 2001; Ware, Kosinski, & Keller, 1996a). Memories become de-contextualised (Craik, 2000), and performing tasks like posting letters or taking medication may be more difficult due to short term memory problems or attention difficulties. However, knowledge about the world, vocabulary and semantic knowledge remains intact or grows with age (Lawton et al., 1999b; Park, 2000). The following section explores how the above cognitive functioning domains are measured in older age.

#### CHAPTER THREE: MEASURING COGNITIVE FUNCTIONING AND CHANGE

Key questions involved in studying cognitive ageing are; when do age-related changes in mental abilities begin? How rapidly do they progress? What factors accelerate or retard them? (Rabbitt, Diggle, Smith, Holland, & Mc Innes, 2001). Cognitive assessment can aid in answering these questions and is routinely used in: screening for cognitive impairment, diagnosis, rating of severity and monitoring disease progression. Methods and measures that are used to assess cognitive functioning are presented below.

Longitudinal studies represent the most powerful designs for describing change and investigating the causal linkages between cognitive performance and its precursors and consequences. Longitudinal data can make a unique contribution to understanding and analysing the burden of diseases for individuals and the implications this has for their experience of cognitive ageing and need for care or other intervention measures. Longitudinal studies have shown that subtle cognitive changes can be measured over just short periods of time; 3 years (Hultsch et al., 1992) through to 12 years (Arenberg, 1990), especially in older age groups (Albert et al., 1993). In a longitudinal study using the Cambridge Cognitive Examination (CAMCOG), over four years, there were significant changes in orientation, language, memory, attention, praxis, abstract thought and perception (Cullum et al., 2000). It is difficult to judge whether the decline was caused by a few individuals who developed dementia (bringing the mean down), however over 50% of the sample showed decline in at least three areas of cognition.

Longitudinal studies can also underestimate change due to practice effects, selective attrition, and can be influenced by society, political policy or cultural changes (e.g., cohort effects), (Salthouse, 2004). Regression to the mean may give the impression of decline in subscales (Morris & Price, 2001) or the ceiling effect may have masked greater decline in high functioning individuals at baseline concealing the full extent of cognitive decline. In Cullum's longitudinal study it is possible that the decline is accounted for by the large number of participants scoring maximum at the baseline in some of the subscales and therefore the test may not have been sensitive to

spurious improvement. When examining change and rate of change in longitudinal studies these factors need to be taken into account.

Cognitive screening tools offer a quick, objective initial assessment of cognitive functioning. Whilst they are not sufficient to make a diagnosis, they can be used as part of a comprehensive assessment. Choosing appropriate measures for assessing cognitive change in longitudinal studies is difficult. In addition to a cognitive measure showing validity and reliability, it must also be: easily understandable, cover a broad range of cognitive domains, differentiate across the diverse range of cognitive abilities without ceiling or floor effects, be sensitive to change, not show practise effects and must be administrable in a survey with lay interviewers. There are additional challenges to assessing cognition in large representative samples such as travelling to people's homes and having short unobtrusive, non-alienating measures.

The Health and Retirement Study and Asset and Health Dynamics Among the Oldest Old (HRS/AHEAD) study in the United States (Ofstedal, Fisher, & Herzog, 2005) was ground breaking in its attempt to include cognitive measures in its longitudinal study and many subsequent large scale longitudinal studies have followed suit. Table 1 showcases the variety of sub-tests that have been used to measure cognitive functioning in some large scale population based longitudinal studies.

	HRS	ELSA	KLoSA	SHARE	ALSA	
	N=26,000+	N= 9,771	N=~1000	N = 55,000 +	N = 2087	
Age of participants	50+	50+	45+	50+	70+	
Cognitive tasks		,				
Self-rated memory (present)	$\checkmark$	$\checkmark$				
Self-rated memory						
(compared to past)						
Orientation to time	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	
Recall (immediate and	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$		
delayed)						
Prospective memory		$\checkmark$				
Serial 7's	$\checkmark$		$\checkmark$		$\checkmark$	
Numeracy	$\checkmark$	$\checkmark$		$\checkmark$		
Number series (digit span)	$\checkmark$					
Similarities	$\checkmark$				$\checkmark$	
Vocabulary	$\checkmark$				$\checkmark$	
Letter Cancellation		$\checkmark$				
Verbal Fluency		$\checkmark$	$\checkmark$			
Object Naming	$\checkmark$				$\checkmark$	
Counting backwards	$\checkmark$					
Anterograde memory	$\checkmark$					
Digit Symbol Coding					$\checkmark$	

Table 1: Cognitive sub-tests used in longitudinal studies

<sup>\*</sup>HRS= Health and Retirement Study (US) (Ofstedal et al., 2005), ELSA = English Longitudinal Study of Aging (Steel, Huppert, McWilliams, & Melzer, 2003), KLoSA= Korean Longitudinal Study of Aging (Jang et al., 2009), SHARE = The Survey of Health, Ageing and Retirement in Europe (Engelhardt, Buber, Skirbekk, & Prskawetz, 2008), ALSA= Australian Longitudinal Study of Ageing (Centre for Ageing Studies, 2006).

The studies highlighted in Table 1 have been innovative in their attempt to include cognitive measures in longitudinal research and identify possible cognitive deficits and dementia related declines. The cognitive tasks used in these longitudinal studies tend to come from a variety of sources; primarily from the isolation of cognitive tasks from: the Mini-Mental Status Examination (MMSE, Folstein, Folstein, & McHugh, 1975; orientation, anterograde memory, counting backwards, serial 7's), standardised neuropsychology batteries such as the Wechsler intelligence and memory scales (WAIS and WMS, Wechsler, 1955: numeracy, similarities, vocabulary, letter cancellation, digit symbol coding and digit span) and the Telephone Inventory of Cognitive Status (TICS, Brandt, Spencer, & Folstein, 1988).

Cognitive screening measures are widely used in New Zealand at a primary health level but not in any longitudinal studies of ageing, other than the Dunedin Multidisciplinary Longitudinal Study which measured intelligence (the oldest participants now being approximately 38), (Dunedin Multidisciplinary Health & Development Research Unit, 2013). The most commonly used screens of cognitive functioning in New Zealand are the MMSE, Clock Drawing Test (CDT), Modified mini-mental status exam (3-MS) and the Addenbrooke's Cognitive Examination (ACE-R), (Strauss, Leathem, Humpries, & Podd, 2012 ). There has been no comprehensive review of cognitive screening within the New Zealand context but a number of international researchers have summarised some of the more popular cognitive screening tools (Cullen, O'Neill, & Evans, 2007; Lonie, Tierney, & Ebmeier, 2009; Shulman et al., 2006; Woodford & George, 2007) and an amalgamation of these are presented in Table 2. They are listed by name and denote the cognitive domain assessed in the screening test.

	CDT	GPCOG	TICS	MMSE	MOCA	3-MS	CASI	ACE-R	CAMCOG
Cognitive Domain									
Memory									
Semantic		$\checkmark$			$\checkmark$			$\checkmark$	$\checkmark$
Short term	$\checkmark$		$\checkmark$						
Long term		$\checkmark$	$\checkmark$		$\checkmark$			$\checkmark$	
Recognition			$\checkmark$					$\checkmark$	$\checkmark$
Attention/Orientation	$\checkmark$								
Language				$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Verbal Fluency						$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Visual-construction	$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Visual-spatial	$\checkmark$	$\checkmark$			$\checkmark$			$\checkmark$	$\checkmark$
Frontal/executive or reasoning/judgement	$\checkmark$	$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	
Mental Tracking			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	
Calculation			$\checkmark$	$\checkmark$	$\checkmark$		$\checkmark$	$\checkmark$	$\checkmark$
Tactile perception									$\checkmark$
Visual perception							$\checkmark$	$\checkmark$	$\checkmark$
Visual memory							$\checkmark$		$\checkmark$
Verbal recognition					$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$
Semantic knowledge		$\checkmark$			$\checkmark$			$\checkmark$	$\checkmark$
Clock drawing	$\checkmark$	$\checkmark$			$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	
Number of points available	3-5	9	39	30	30	100	100	100	105
Average time (min)	2	5	5-10	8	10-15	10-15	15-20	15-20	30
Internal consistency	0.93	0.80-0.84	0.87	0.86	0.83	0.82		0.80	
Inter-rater reliability	0.98	0.56-0.75	0.97	0.83	0.81	0.98		0.99	
Test-retest reliability	0.86	0.84-0.87	0.90	0.89	0.70-0.92	0.85		0.88	
Validity (construct)	0.73	0.68	0.85	0.66-0.77	0.87	0.95	0.4-0.9	0.8	
Diagnostic Utility									
Cut-off *			<25	<26	<26	<78	<78	<82	<80
Sensitivity %*	~85	85	1.00	69-91	90	83-94	87.9	84-94	92
Specificity %*	~85	86	0.83	87-99	87	85-90	85.7	89-100	96

Table 2: Comparison of commonly used assessment tools relative to aspects of cognitive functioning

\*CDT, Clock Drawing Test; GPCOG, the General Practitioner Assessment of Cognition; MOCA, Montreal Cognitive Assessment; 3-MS, Modified Mini Mental Status Examination; CASI, Cognitive Abilities Screening Instrument; ACE-R, Addenbrooke's Cognitive Examination; CAMCOG, Cambridge Cognitive Examination. \*sensitivity refers to the proportion of people who have an impairment who are classified by the screen as impaired; specificity refers to the proportion of people who do not have an impairment who are classified by the screen as unimpaired. †Note that several basic cognitive abilities may contribute to a level of performance on these tasks.

Many of the above named screening tools perform well, eliciting information about key cognitive abilities, with robust validity and reliability. However, it has been suggested that large scale studies that have included cognitive measures rarely use sufficiently sensitive and broad ranging tests of cognitive function to enable investigation of change in different cognitive domains (Cullum et al., 2000). There is a necessary trade-off between brevity and extensiveness that must be made in longitudinal studies and it is possible that these trade-offs impact on the quality of data gathered. For example, the MMSE, (Folstein et al., 1975) is the most commonly used cognitive screening tool (Shulman et al., 2006). It is a thirty point assessment tool initially developed as a screening test to distinguish organic from non-organic cognitive disorders and is now commonly used to screen for and monitor the progression of dementia, correlating well with a number of neuropsychological tests. Many studies use the popular MMSE which has more recently been highly criticized for: scores being biased by baseline education level, language and cultural factors (Chatfield, Matthews, & Brayne, 2007; Christensen, 2001; Lonie et al., 2009), showing ceiling and floor effects (Tombaugh & McIntyre, 1992), not assessing many domains, and having too few items that test executive functioning and visual-spatial functions (Bak & Mioshi, 2007). It also has an over-reliance on verbal cognitive functioning to assess memory and attention, and is insensitive to frontal-executive dysfunction and visual-spatial deficits (Mioshi et al., 2006a). Furthermore, the validity of using individual components of the Wechsler scales may be questionable as validity is assessed based on the measure as a whole rather than component items (therefore challenging the content validity), and use of telephone administered assessment means that there is no visual assessment and participants require good hearing to participate. With poor choice of cognitive measures it is likely that more subtle changes will be missed and tests will not be able to discriminate well within the range of cognitive domains.

A potentially useful cognitive screen, the Addenbrooke's Cognitive Examination (ACE), is a 10-15 minute cognitive screening measure used to detect problems relating to memory, orientation, language, perception, visual-constructional and verbal fluency (Mioshi et al., 2006b). Weaknesses that were found with the original ACE (Mathuranath, Nestor, Berrios, Rakowicz, & Hodges, 2000), such as limited cross-cultural validity, ceiling effects and limited visual-spatial components, were addressed with the revised version, (Mioshi et al., 2006a). The revised version, ACE-R, differentiates between Alzheimer's disease and fronto-temporal dementia (FTD) (Mathuranath et al., 2000), differentiates between cognitive impairment and affective disorders (Dudas, Berrios, & Hodges, 2005) and has sensitivity that is comparable to the Dementia Rating Scale (Mioshi et al., 2006a). It is used for detecting the presence of cognitive impairment in patients with Parkinson's disease (Chade et al., 2008) and is a better single predictor of dementia compared to picture naming and MRI scans (Galton, Erzinclioglu, Sahakian, Antoun, & Hodges, 2005). It provides an MMSE score which enables cross-cultural comparisons to studies that still use the MMSE but extends and improves the MMSE with lower ceiling effects (expanding the points available), improved sensitivity and assessment of more cognitive domains, particularly components for memory and frontal/executive functioning. The ACE-R consistently outperforms the MMSE, increasing estimates of cognitive ability by 16% (Law, Connelly, Randall, 2012)<sup>1</sup>. It has been translated into at least 20 languages and validated for a number of different countries (Alexopoulos, Mioshi, Greim, & Kurz, 2007; Garcia-Caballero et al., 2006; Konstantinopoulou, Kosmidis, Kiosseoglou, Karacostas, & Taskos, 2010; Mathuranath, Cherian, Mathew, George, & Sarama, 2006; Taylor, 2008).

## Domains covered by the ACE-R are:

## Attention/Concentration (18 points)

- Orientation in time and space, registration of three words, and serial subtraction/backward spelling. This subtest measures the ability to hold information in the mind. It requires

<sup>&</sup>lt;sup>1</sup>Since this study was conducted the MMSE has been copyrighted. As a result the ACE-R is no longer legally allowed to incorporate the MMSE items. The ACE-R III, which does not contain the MMSE, is currently being developed and early studies show equivalency with the earlier ACE-R, despite changes to the items (Hsieh, Schubert, Hoon, Mioshi, & Hodges, 2013).

attention and concentration. It is measured using immediate memory tasks. The inability to attend and sustain that attention can affect all other cognitive domains.

# Memory (26 points)

- Working memory, short term memory, retrograde and semantic memory, anterograde memory, recall and recognition using mixed contextual and non-contextual information.

# Language (26 points)

Assesses language and praxis. Comprehension, repetition, writing, naming and reading.
 Repetition of single words and phrases, naming pictures of low frequency items (for example, anchor, rhinoceros), comprehension relating to these items and reading irregular words (for example, pint, dough). These tasks were developed to show dysphasia or paraphasia and can also highlight word finding difficulties, visual misperceptions or semantic problems.

# Visual-spatial (16 points)

- Assesses non-verbal skills. It can be used to test for constructional praxis, executive function difficulties (planning, abstract thinking), visual fields, counting strategies. The clock drawing tasks draws on executive functioning (planning, abstract thinking) and also motor and visual-spatial abilities. The more perceptual tasks analyse visual fields, executive functioning (tracking and sequencing) and visual perception with diminished cues.

# Verbal Fluency (14 points)

- Letter fluency (as many words as possible starting with the letter 'p') and category fluency (as many different animals as possible) draws on executive function and semantic memory.

Reviews of cognitive screening tests suggest that the ACE-R is a useful, and in some cases, the ideal tool to screen for cognitive difficulties (Cullen et al., 2007; Lischka, Mendelsohn, Overend, & Forbes, 2012; Lonie et al., 2009; Woodford & George, 2007). Table 3 shows the original ACE

(before the revised version) in comparison to other screening tests (Woodford & George, 2007, p.

472).

Cognitive domain	AMT4	CDT	SIS	Mini-	AMT	6CIT	GPCOG	MMSE	ACE
				cog					
Memory									
- Semantic	-	+	-	+	+	-	+	-	++
- Short term	-	-	+	+	+	++	++	+	+++
- Remote	+	-	-	-	+	-	-	-	++
Visuospatial/Constructional	-	++	-	++	-	-	++	+	+++
praxis									
Frontal/executive	-	+	-	+	-	-	+	-	++
Orientation	+	-	+	-	++	++	+	++	+++
Attention/Calculation	-	+	-	+	++	++	+	++	++
Language	-	-	-	-	-	-	-	++	+++
Other aspects									
Informant content	-	-	-	-	-	-	+	-	-
Equipment required	-	Pen and paper	-	Pen and paper	-	-	Pen and paper	Pen, paper, watch	Pen, paper, watch and series of
Average time needed/min	1	2	2	3	3	5	5	8	specialized pictures 20

Table 3: Commonly	used measures of	f Cognitive	Functioning
Table 5. Commonly	used measures 0	Coginate	runctioning

-, not specifically tested; +, minimal assessment; +++, relatively extensive assessment.

The ACE and its revised version (ACE-R) performed well against other cognitive screening measures. In the past decade the ACE has been cited as a potentially useful screening tool in guideline documents by the National Institute for Health and Clinical Excellence (National Institute for Health and Clinical Excellence (NICE), 2006). The ACE-R has been used in one community focused longitudinal study in the United Kingdom and was found to be sensitive to cognitive decline, stability and improvement in cognitive functioning and deemed a good measure for cross-sectional and longitudinal assessment of cognitive disorders (Larner, 2009). There are some caveats to using the ACE-R; the administration time is longer compared to other screening measures, it does not measure processing speed, (a hallmark feature for cognitive ageing) and it is used primarily for clinical populations. Some studies, particularly those using non-European

samples have found large education effects (Kwak, Yang, & Kim, 2010; Mathuranath et al., 2000).

The ACE-R has been used extensively in New Zealand hospitals and been noted as having better predictive utility over the 3MS and the MMSE (Strauss, 2013). The ACE-R has been modified for use with New Zealanders, in accordance with suggestions from the developers; changes made are more site specific anterograde, retrograde and delayed recall memory components were modified to make the ACE-R more culturally acceptable (the 'Kiwi' ACE-R; Taylor, 2008). For example, using a New Zealand address to learn and recall and recalling the current New Zealand Prime Minister rather than the US President. It is unclear whether these small changes affect the psychometric properties of the measure as this has not been studied either in New Zealand. Other countries have also followed these guideline changes and have found little change to the psychometric properties of the measure (Alexopoulos et al., 2007; Garcia-Caballero et al., 2006; Konstantinopoulou et al., 2010). Overall, the ACE-R is a valid and reliable measure (Mioshi et al., 2006a), is freely available, can be administered by lay interviewers and has extensive assessment of domains across a number of items which are not as susceptible to floor and ceiling effects (Woodford & George, 2007).

# Summary

The assessment of cognitive functioning requires valid and reliable measures. Unfortunately, many longitudinal studies use a 'pick n mix' of cognitive tasks drawn from a variety of sources which likely reduces the validity of the assessment and they also rely on outdated measures. Within large longitudinal studies, the need for brevity, ease of administration and accuracy makes the choice of a cognitive screening tool the best option. Reviews of acceptable tools often show that the ACE-R is a valid and reliable tool which has the potential to be useful in longitudinal studies.

What follows is a journal article presented as a manuscript for publication that reports the results of a pilot study on the feasibility of using the Kiwi adapted version of the ACE-R to measure cognitive functioning in older adults.

# Study One: Cognitive Functioning in Older New Zealand Adults: A Pilot Study on the use of the Addenbrooke's Cognitive Examination –Revised.

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#### Abstract

As the New Zealand population ages there is a growing need to ascertain and provide for the needs of older adults. Impairmed of cognitive functioning in decreases the ability to undertake activities of daily living and can impact significantly on the ability to sustain independent living. The rate of cognitive impairment in New Zealand among older adults is unknown and the accuracy of assessments of older adults is questionable. This current study is a pilot to assess the validity and utility of the 'Kiwi' Addenbrooke's Cognitive Examination – Revised (ACE-R) for use in a longitudinal study of older New Zealanders. The cognitive functioning of forty-five older community dwelling adults was measured. Results suggest that the 'Kiwi' ACE-R is a valid and useful measure of cognition for older people in New Zealand and can be used in longitudinal studies of ageing of community dwelling older adults.

# Introduction

Due to the rapid ageing trend across many populations in the world, ageing has become increasingly recognised as a vital issue facing individuals, families, communities and nations. Estimates of the world's population aged over 60 have more than doubled from 1960 (225 million) to 1990 (450 million) and that number is set to increase substantially by 2051 with over 25% of the developed region's population estimated to being over 60, outpacing the growth of all other age groups (Statistics New Zealand, 2012).

New Zealand shows the same ageing trend as the developed world due to the continual increase in life expectancy and the post WWII 'baby boomers' entering retirement age. In 1901 4% of the

New Zealand population was aged over 64 years of age, and. similar to world projections, this age group has had a dramatic increase in numbers with 13% falling into the 65+ category in 2006 and a projected increase to 25% of all New Zealanders in 2051 (Statistics New Zealand, 2012). This pervasive and enduring population trend opens up many opportunities and challenges which the New Zealand government has highlighted as a national priority (Ministry of Health, 2007).

With the increase in older adults there is a need to further develop understanding of this population and their specific requirements. The increased physical and mental health needs of this growing population group has major implications for community, primary health, and residential care services. There is likely to be a greater demand for residential support and health and disability services, including specialist services for older adults (Te Pou, 2011). The New Zealand government has reflected this with specific ageing policies. For example, there has been a strong push towards maintaining older people's independence in their own homes and developing community based models of care that reduce the need for institutionalized, or residential care (Ministry of Social Development, 2001; Parsons et al., 2012).

Cognitive decline, which is a hallmark of ageing, is the leading cause of institutionalization of older people (National Institute on Aging & National Institutes of Health, 2007) and therefore there is a need to support those people who show impairment to stay in their homes for longer and maintain their quality of life.

# Declining cognitive functioning

Cognitive ageing refers to a pattern of age-related changes of cognitive functioning. Common problems include forgetfulness, word finding difficulty, slowed reaction time and difficulty learning new tasks. Declining cognitive functioning is a common feature of ageing, with 50% of adults over 60 years of age expressing concern about declining mental abilities, with one of the most common complaints among middle-aged and older adults being that their memory is not as good as it used to be (Lachman, 2010).

A decline in adequate cognitive functioning can impact the ability to perform instrumental activities of daily life (e.g., paying bills, medical regimes, planning activities) and activities of daily life (e.g., dressing, bathing) (Brown, Devanand, Liu, & Caccappolo, 2011). It is also a significant indicator of overall health (Anstey, Luszcz, Giles, & Andrews, 2001), associated with increased rates of hospitalization and mortality (Anstey et al., 2001; Herzog & Wallace, 1997; Matusik, Tomaszewski, Chmielowska, Nowak, & Nowak, 2012), reduced quality of life, increased disability and increased health care costs (Plassman et al., 2008). These impairments play a pivotal role in relation to health care utilization among older adults and can also impact economically by affecting work, decision making and retirement (Lachman & Spiro, 2002)..

Accurate estimates of the national prevalence of cognitive impairment are important for determining the financial and social impact of reduced cognitive functioning. Estimates of cognitive impairment in community samples vary depending on what criteria are used and what population is sampled. Longitudinal studies find rates of cognitive impairment, (not dementia), ranging from 4-35% in the community with an exponential increase in impairment 1.7 times higher than previous age groups (Herzog & Wallace, 1997). A longitudinal study in the United Kingdom had estimates of impairment ranging from 2.3% (65-74 years old), 7.2% (75-84 years old) and 21.9% (85+), (Melzer, Ely, & Brayne, 1997). A population-based study in Finland examined the prevalence of age associated cognitive decline and found a rate of 27% in people aged between 68 and 78 years (Hanninen et al., 1996). The Health Retirement Study/Asset and Health Dynamics Among the Oldest Old (HRS/AHEAD) study found that in the community, an estimated 6% of people aged 70 years and older have moderate to severe cognitive impairment and this increased sharply with age (Suthers, Jung, & Crimmins, 2003). This was the first time nationally representative data assessing cognitive function in older people was gathered and it has continued longitudinally (National Institute on Aging & National Institutes of Health, 2007). Given the high and varied rates of cognitive impairment within communities, the assessment and treatment of cognitive functioning represents an important component of geriatric care and

suggests a need for standardised assessment and criteria to assess cognitive functioning in older adults.

A national report about the mental health of community dwelling New Zealanders stated that "due to either the unavailability of data or the lack of reliable data, these indicators [for dementia] could not be included in this report" (Ministry of Health, 2006, p. 2). The exclusion of rates of cognitive impairment in the mental health literature represents a significant gap in research and has policy implications in terms of planning and expenditure in this area for the upcoming influx of older adults. One early study has suggested that the prevalence rates of dementia in New Zealand are around 7.7% for people aged over 65, with around 30% of those over 85 having dementia (Campbell et al., 1983). This is a dated study and rates of dementia are likely to have significantly changed since then due to the comparative increase in the older population and better assessment. Therefore, there is a need for more up to date and accurate predictions of cognitive functioning levels. As yet, there is no known reovsearch regarding the prevalence of cognitive functioning difficulties in different ethnic groups and further our knowledge of the specific risk factors that give rise to cognitive functioning difficulties.

# Assessing cognitive functioning

Accurate assessment, capable of identifying individuals that are showing cognitive change is a prerequisite to effective post-diagnosis support, or early intervention. Early detection of cognitive impairments is a challenge but screening for early impairments has become more important with the 'work up' offering the best opportunity for secondary prevention (Shulman et al., 2006) in early stages of cognitive decline (Crawford, Whitnall, Robertson, & Evans, 2012). For example, disease-modifying treatments, such as medication and lifestyle change factors (Benerjee & Wittenberg, 2009) could be introduced earlier. The New Zealand 2008 Dementia Manifesto (Alzheimer's New Zealand, 2008), emphasised the need for early diagnosis and dementia-specific

training for primary health staff as dementia is often only diagnosed at a late stage, because primary care settings are not geared to routinely screen for cognitive impairment (Boustani, Peterson, Hanson, Harris, & Lohr, 2003). Population-based studies find the prevalence of undiagnosed dementia among those over 65 years ranging from 1.8% (Sternberg, Wolfson, & Baumgarten, 2000) to 12% (Boustani et al., 2003). It is estimated that in New Zealand only a third of those with dementia receive a diagnosis (National Audit Office, 2007). Routine screening, with accurate measures could, therefore, potentially increase substantially the number of people diagnosed with dementia, and newly discovered cases would have mild to moderate forms of the disease. Thus there is a national priority for service providers to increase the ability to accurately detect signs of cognitive decline. Studies have found that cognitive performance strongly predicts pathological diagnosis of Alzheimer's Disease (AD) over six years of follow-up with a diagnostic accuracy of 75% (Elias et al., 2004) and over longer follow-ups of twenty-two years on measures of verbal fluency, with one standard deviation difference in baseline performance increasing the risk of AD by 60% (Powell et al., 2006). These studies highlight the need and appropriateness for early assessment and intervention.

There has been a substantial increase in the development of evaluative methods in the screening of cognitive functioning in older adults (Witta & Sivo, 2002). Cognitive screening tools offer a quick, objective initial assessment of cognitive functioning. Whilst they are not sufficient to make a diagnosis, they can be used as part of a comprehensive assessment.

Longitudinal or prospective surveys represent the most powerful designs for describing change and investigating the causal linkages between cognitive performance and its precursors and consequences. It is commonly believed that cognitive functioning exists on a continuum, in which mild cognitive impairment represents a transition state between normal cognitive ageing and dementia (Gauthier et al., 2006; Prichep et al., 2006). Whilst not all people continue along the continuum it highlights the importance of assessing cognitive performance difficulties in older people longitudinally, as cognitive difficulties can be progressive, meaning that prevention or intervention may be possible at a stage along the continuum. Longitudinal studies provide information that cross-sectional studies cannot such as estimates of individual rates of decline, risk factors for decline and data on correlations between changes in cognitive ability and changes in other non-cognitive domains. Longitudinal studies have shown that subtle changes can be measured over just short periods of time (e.g., 2-2.5 years), especially in the oldest age groups (Albert et al., 1993). However these studies can also underestimate change due to practice effects and selective attrition and can be influenced by society or cultural changes (Salthouse, 2004). Longitudinal studies, like cross-sectional, can also comment on how cognitive functioning may vary across individuals. For example, research commonly finds an association between measures of depressive and anxiety symptoms and cognition, finding that those people who show significant signs of depressive or anxiety symptoms perform more poorly on cognitive measures; however, the mechanisms are unclear, (Beaudreau & O'Hara, 2009; Gonzáleza, Bowena, & Fisher, 2008; La Rue, Swan, & Carmelli, 1995). Furthermore, cognitive functioning may be altered depending on demographic variables (e.g., age, sex, education).

Many large health studies do not typically look at cognition (Lachman & Spiro, 2002; Ofstedal et al., 2005). It is assumed that reliable cognitive measurements are too difficult and time consuming to administer in a survey format by lay interviewers. Furthermore, poor response rates, institutionalisation of those at risk and cognitive impairment can affect data collection and quality of responses. Due to the suspected difficulties of assessing cognitive function on a large population based level there have been limited studies of community based cognitive functioning and the quality of the data from these studies may be compromised.

#### Summary

The current lack of knowledge about base rates of cognitive function in New Zealand makes it difficult to derive reliable and valid national impairment estimates, develop explanatory models of cognitive changes and predict the needs of this growing population for policy and care implementation. Measuring cognitive functioning is essential because it helps to characterise; what normal cognitive ageing is, what aspects are protective for quality of life, the role of demographic variations in cognitive functioning and how it can be an important resource in later life as a moderator of differences in health, functional capacity and retirement (Lachman & Spiro, 2002). There have been no population based studies in New Zealand investigating the cognitive functioning of older adults living in the community. Through the piloting and use of New Zealand adapted cognitive measures we can assess the validity and utility of the measures with this population which will help create a more accurate picture of cognitive functioning and open up research opportunities to begin addressing many of these issues facing our ageing nation.

# The current study

The current research project is a pilot study to investigate the feasibility of using the adapted 'Kiwi' version of the ACE-R in the New Zealand Longitudinal Study of Ageing (NZLSA)<sup>2</sup>. This paper represents the first steps towards identifying community levels of cognitive functioning in New Zealand and provides a context from which the development on New Zealand norms and assessment of cognition in longitudinal studies can be facilitated. This research aims to:

- Pilot the use of the Kiwi adapted ACE-R with older New Zealanders.
- Determine the feasibility of using the "Kiwi"ACE-R within the NZLSA
- Note whether the ACE-R is influenced by psychological (depression and anxiety symptoms) or demographic variables (e.g., age, sex, education).

# Method

## **Participants**

The sample consisted of forty-five community dwelling volunteers from the wider Wellington region. Participants were recruited through; community notices, emails to age-associated organizations and word of mouth (see Appendix A). Ages ranged from 56-87 (mean = 71.6, SD

<sup>&</sup>lt;sup>2</sup> The NZLSA is a population based longitudinal study following a national sample of over 4,000 New Zealanders with the aim to discover what factors lead to good retirement planning, health and independence in older people. It is a collaboration between Massey University and the Family Centre Social Policy Research Unit.

=7.8). The age range chosen reflects both the guidelines given by the longitudinal study, as well as capturing age groups that may have been more susceptible to cognitive change. There were 27 females and 18 males. The majority of the sample was of European ethnicity (86.7%), over half of the sample was married (53%) and others were mostly either divorced (15.6%) or widowed (15.6%). Overall this sample was well educated, having obtained a university degree (35.6%), finished high school or achieved a post-secondary qualification (58%). Table 4 summarises the participants' demographic information that was used in the analysis.

Table 4: Summary of Demographic Information

	Number n=45	Percentage %
	Mean = 71.6	
Age	Range = 56-87	
Gender	10	
Male	18	40
Female	27	60
Ethnicity	20	94 <b>7</b>
New Zealand European	39	86.7
Other	9	13.3
Marital Status		
Single	3	5.7
Married	24	53.3
Divorced	7	15.6
Widowed	7	15.6
De-facto		4.4
Other	2 2	4.4
Living arrangement		
Alone	4	31.1
With partner/De-facto	24	53.4
Other	7	15.6
Qualification Level	2	
No qualifications	3	6.7
Secondary school	14	31.1
Post-secondary/trade	12	26.7 25.5
University degree	16	35.5

# Procedure

Promotional material and emails were sent to community organizations to advertise the study (see Appendix A)<sup>3</sup>. People who indicated an interest in participating were contacted via telephone or email and provided with more details about the study, (see Appendix B). Participants residing in the community (i.e., non-institution) were interviewed, as the focus for this study was a community-based, non-clinical sample. Informed consent was gained (see Appendix C) and interviews arranged with those who indicated an interest, with the majority of participants interviewed in their own residence. All interviews were conducted by the author. Participants were first administered a demographic questionnaire, followed by depression and anxiety symptom questionnaires and finally the cognitive assessment. Each participant interview took

<sup>&</sup>lt;sup>3</sup> Appendices are included for the thesis but will not be part of the manuscript submitted for review.

approximately an hour. All participants were thanked for their time with either a choice of a \$10 petrol voucher or \$10 worth of instant scratchie tickets.

#### Measures

*Demographic questionnaire*. The demographic questionnaire was based on the 2006 New Zealand census demographic information (e.g., gender, age, ethnicity, qualifications, Statistics New Zealand, 2008). The questionnaire included questions relating to participants' subjective ratings of their current level of physical health and ratings of their current level of memory ability and their memory ability compared to two years ago.

*Addenbrooke's Cognitive Examination-Revised (ACE-R).* The ACE-R is a cognitive screening measure designed to screen for dementia. It is scored on a scale from 0-100 and assesses five cognitive domains: Attention/Concentration (18 points), Memory (26 points), Verbal Fluency (14 points), Language (26 points) and Visual-spatial (16 points).

The ACE-R was originally normed using a control group (N=63) and this group was used to demark cut-off scores for dementia, (<2 standard deviations below the norm) and mild cognitive impairment, (<1.5 standard deviations below the norm). The control group was recruited from a U.K. volunteer panel at the Medical Research Council Brain Sciences, or were spouses of patients attending the memory clinic. The sample was 44% male, had an average of 12.7 years of education and an average age of 64.4 years old. Ethnicity was not noted. The ACE-R showed very good internal consistency, (as measured by the alpha coefficient,  $\alpha$ =0.80) and concurrent validity between ACE-R and Clinical Dementia Rating Scale (CDRS) (r=-0.321, p<0.00). There was no significant age or education effect on scores (Mioshi et al., 2006a).

Two cut-off scores have been proposed that demark likely cognitive impairment (Mioshi et al., 2006a). A cut off score of <88 gives 0.94 sensitivity (i.e. it misses 6% of cases) and 0.89 specificity for dementia (i.e. 89% of cases are dementia rather than another difficulty like

depression). A cut off score of <82 gives 0.84 sensitivity (i.e., misses 16% of cases) and 1.00 specificity for dementia (i.e., all cases identified are dementia).

*Other cognitive measures.* To allow for cross-country comparisons of data, measures used in a large representative longitudinal study in the United States, the Health Retirement Study (HRS), were included. The HRS used questions which are an amalgam of items from the Wechsler Intelligence Scale-Revised, (which was the most recent version of the scale at the time the longitudinal study commenced) and the Telephone Interview for Cognitive Status (TICS). Items assessed memory, (e.g., immediate, delayed and working), mental status (e.g., knowledge, language and orientation), abstract reasoning (e.g., similarities subtest), vocabulary (e.g., definitions) and numeracy (e.g., math problems). Results are publicly available and allow for cross-nation comparisons of cognitive ability on these items (see Herzog & Wallace, 1997 for a review of the cognitive measures over different wave years).

Depression and Anxiety symptoms. To see whether depressive or anxiety symptoms impacted on ACE-R scores, measures of depression and anxiety were chosen and are outlined below. Two measures of depressive symptomology were included in this study due to the dissatisfaction of some participants with the Geriatric Depression Scale. Participants who were piloted felt that the scale was too restrictive in the options available for answering questions. Due to this, the Centre for Epidemiological Studies Depression Scale was introduced as a further measure of depressive symptoms.

*Center for Epidemiologic Studies Depression Scale (CES-D 10).* Developed in the United States by Radloff (1977), the CESD is a self-report scale designed to screen for depressive symptoms in general populations, with an emphasis on depressed mood over the last week. Each item is rated on a four-point scale, scored from 0 to 3. An example of an item measuring depressive affect is "*I was bothered by things that don't usually bother me*". The psychometric properties of the CES-D 10 item are comparable with the original 20-item scale with reliability coefficients ranging from

0.85-0.91 and test re-test reliability studies show moderate correlations (r=0.51-0.67) (Irwin, Artin, & Oxman, 1999). Validity ratings between other depression measures (Symptom Checklist-90, Hamilton Rating scale for Depression and the Geriatric Depression Scale) range from 0.49-0.89 (Radloff & Locke, 2000). Using an optimal cut-off score of 4 the sensitivity of the 10-item CES-D was 100% and specificity, 93% (Irwin et al., 1999), when used with adults over 60 years of age. New Zealand studies suggest good internal consistency with mature older adults, ( $\alpha$ =0.88-0.92) (Brown, Jose, Hung Ng, & Guo, 2002) and middle aged women (Knight, Williams, McGee, & Olaman, 1997).

The CES-D was chosen for the current study because it has demonstrated suitability for older populations (Brown et al., 2002), including New Zealand and it has widespread use internationally, which both attests to its reliability and validity for a variety of subpopulations, and allows for greater comparability with existing research. The CES-D has been used in a number of large epidemiological studies including; the National Health and Nutrition Examination Survey (NHANES), the Established Populations for Epidemiologic Study of the Elderly (EPESE), the National Longitudinal Surveys (NLS Mature Women, NLS-Older Men, NLSY), and the Americans' Changing Lives study (ACL).

*Geriatric Depression Scale (GDS-15).* The Geriatric Depression Scale (GDS) is a widely used self-report measure of depressive symptoms felt over the last week (Yesavage et al., 1982). It is used as a screen for depressive illness, severity of depression and monitoring of change with treatment. The measure is answered in a yes/no format. An example of an item assessing depressive affect is, "*do you feel that your life is empty?*" The 15 item version of the GDS (GDS-15) was found to be a good screening instrument for major depression as defined by both the ICD-10 and DSM-IV (Almeida & Almeida, 1999). The reliability of the scale has been found to be high, averaging 0.84 and test –retest reliability over one month is high (r=0.85), (Kieffer & Reese, 2002). It has good convergent validity with depression measures such as the Beck's Depression Inventory (BDI-II) and the Hamilton Depression Rating Scale and discriminates

between older adults with depression and no depression (O'Hara & Yesavage, 2002). A cut off score 4/5 for the GDS-15 provides 92.7% & sensitivity and specificity of 65.2% (Almeida & Almeida, 1999). A New Zealand study of 252 healthy volunteers found support for the use of the GDS with findings of high alpha coefficients ( $\alpha$ = 0.84), test retest reliability (Pearson's r= 0.74) and construct validity (r= 0.68) (Knight, McMahon, Green, & Skeaff, 2004).

*Geriatric Anxiety Inventory (GAI).* The Geriatric Anxiety Inventory (GAI) is a self-report measure designed to assess common symptoms of anxiety in older adults (Pachana, Byrne, Siddle, Koloski, & Arnold, 2007). It contains 20 items with a dichotomous response format "agree/disagree". An example of an item is, "*I think of myself as a worrier*". In the original paper internal consistency was high,  $\alpha$ =0.91. Convergent validity with a number of other anxiety scales (e.g., the State Trait Anxiety Inventory and Beck Anxiety Inventory and the Positive and Negative Affect Schedule) ranged from 0.70-0.80 (Pachana et al., 2007). A New Zealand study of older adults (n=32, mean age = 75.5) found that a cut off of 8/9 (out of 20) has a sensitivity of 73% and a specificity of 80% in identifying people with an anxiety disorder. (Cheung, 2007).

# Results

# Statistical Analysis

All statistics were performed using SPSS 18.0 (SPSS Inc, Released 2009). Demographic analyses were conducted; ACE-R scores were analysed across the full sample using Pearson correlations, across gender using T-tests for differences between means, and across age groups using a one-way analysis of variance (ANOVA) with Tukey posthoc tests. Reliability was calculated using the Chronbach alpha coefficient (Chronbach, 1951). Concurrent validity was calculated using a two-tailed spearman correlation between ACE-R scores and HRS scores.

# Distribution

Scores on the ACE-R (Figure 1) ranged from 74-99 with a mean of 92.36 (standard deviation=5.51). High scores on the ACE-R were expected as it was developed as a screening test

for cognitive impairment which only affects a minority of the population. The distribution was significantly non-normally distributed, with skewness of -1.42 (standard error = 0.35) and kurtosis of 2.12 (standard error = 0.70).

Figure 1: Distribution of ACE-R scores showing normal distribution curve.

# Reliability and Validity

Chronbach's alpha coefficients were used to test internal consistency of the ACE-R. The Chronbach's alpha for the ACE-R items was  $\alpha = 0.66$  (n=26 items), which is slightly lower than recommended (0.7) for psychometric measures (McDowell & Newell, 1996). The ACE-R total and domains correlated significantly with Pearson correlations ranging from 0.55-0.79. Table 5 lists the inter-correlations between ACE-R total and the domains.

Table 5: Pearson Correlations between ACE-R Subscales and Other Cognitive Tests

Domains	Attention/ Orientation	Memory	Verbal Fluency	Language	Visual-spatial
ACE-R total	$0.55^{**}$	$0.79^{**}$	$0.60^{**}$	$0.59^{**}$	$0.57^{**}$
Attention / Orientation		$0.34^{*}$	0.27	$0.32^{**}$	0.18
Memory			0.14	0.41**	0.20
Verbal Fluency				0.30	0.33**
Language					$0.50^{**}$
Visual-spatial					

\*\*Correlation is significant at the .001 level (2-tailed), \*Correlation is significant at the .05 level (2-tailed)

The spread, means and standard deviations for the total ACE-R and subscales are provided in Table 6. Overall there was a good spread of scores with participants scoring at high and low ends of the ACE-R scale. None of the participants attained a perfect score and there were no extremely low scores, indicating no overall ceiling or floor effects. On individual items there were some ceiling effects. For example, 100% of people identified the fragmented letters correctly and 88% correctly answered questions relating to orientation and knowledge. Only one person incorrectly wrote a sentence, had difficulty copying pentagons and could not immediately recall three objects.

The ACE-R correlated highly with other tasks of cognitive functioning such as the MMSE; r = 0.70, p<.00 and items from the HRS study; r = 0.60, p <.00, suggesting good concurrent validity.

Domains (points available)	Ň	Minimum	Maximum	Mean (SD)
ACE-R total (100)	45	74	99	92.36 (5.51)
Attention/Orientation (18)	45	14	18	17.69 (0.79)
Memory (26)	45	15	26	23.24 (3.14)
Verbal Fluency (14)	45	3	14	11.20 (2.24)
Language (26)	45	23	26	24.87 (1.08)
Visual-spatial (16)	45	11	16	15.33 (1.09)

Table 6: ACE-R Result Summary

Face validity was assessed through participant interviews. The majority of participants found the test straight forward and easy to understand. While some reported confusion about the purpose and meaning of particular tasks, there was no negative feedback about the process (e.g., "this is fun", "it's like being back at school"). Participants had a variety of answers to the picture naming sub-domains, which required interviewer judgement when scoring, (e.g., accepting 'keg' rather than 'barrel' and 'crocodile' rather than 'alligator').

# Comparison to original normed control group

Table 7 provides a comparison of the sub-domains of the ACE-R between the present sample and the original control sample. There were significant differences between the pilot study sample and the original control in the cognitive domain of Visual-spatial. The original control sample scored significantly lower, on this subscale. The effect size was moderate. Overall, the current sample did not differ significantly in ACE-R total score (M= 92.22, SD= 5.66) from the control sample (M=93.7, SD=4.3), t (106) = -1.42, p< 0.16.

Table 7: Two Tailed T-Test comparisons of ACE-R and Sub-Domain Scores between the Current Sample and the ACE-R Original Control Group

Sumple and the ACL R Original Control Group						
Pilot Sample Mioshi contro		Comparison t-tests				
(N= 45, mean age 71.6)	(N=63, mean age 64.4)	(df= 106)				
Mean (SD)	Mean (SD)	t-score (SE Mean)				
92.36 (5.51)	93.7 (4.3)	-1.34 (0.95), p=0.16				
	Pilot Sample (N= 45, mean age 71.6) Mean (SD)	Pilot SampleMioshi control(N= 45, mean age 71.6)(N=63, mean age 64.4)Mean (SD)Mean (SD)				

Attention/Orientation	17.69 (0.79)	17.7 (0.5)	0.08 (0.12), p=0.94
Memory	23.24 (3.14)	23.4 (2.7)	0.28 (0.56), p=0.77
Verbal Fluency	11.20 (2.24)	11.9 (1.7)	1.87 (0.38), p=0.07
Language	24.87 (1.08)	25.1 (1.5)	0.89 (0.26), p= 0.38
Visual-spatial	15.33 (1.09)	15.7 (0.7)	2.15 (0.17), $p=0.03^{**}$
** significant at n< 05			

\*\*significant at p<.05

# Demographic variables

The Pearson correlation between ACE-R score and age was non-significant (r=-0.19, p<0.21). There was no significant difference between male (M=92.06, SD=5.72) and female gender (M=92.56, SD=5.26); t (43) = -0.30, p=0.77, nor across level of qualifications gained;no qualifications (M=91.67, SD=5.19), trade/post-secondary (M=93.08, SD=4.56) and tertiary (M=92.81, SD=6.64); F (3, 44) = 0.38, p<0.77.

# Cognitive Impairment.

Two cut-off scores were developed for the ACE-R in the original development paper based on the calculations of sensitivity and specificity and positive predictive values at different prevalence rates. The likelihood ratio described in that research showed that the more stringent cut-off for impairment of 82 is 100 times more likely (than a score of 88) to come from somebody with dementia than without. At the more stringent cut-off of <82 two people in this sample would be classified as significantly cognitively impaired (4.4%).

#### Depression and anxiety symptomology

The 'Kiwi' ACE-R was not significantly associated with either of the depression scales (CES-D10, GDS15) or the anxiety measure (GAI-20). All the mood scales were significantly correlated with each other (r=0.42-0.57, p<0.00). According to the suggested clinical cut off scores for each of the scales (Brown & Schinka, 2005; Pachana et al., 2007; Radloff & Locke, 2000), seven people met clinical criteria for depression using the GDS, eleven people meet criteria for depression using the CES-D and three people met the cut-off criteria for anxiety using the GAI.

#### Comparison to HRS results

This current sample differed significantly from the HRS scores on the cognitive functioning subdomains. The current sample was significantly poorer at recalling items after a delay. However, this New Zealand sample performed significantly better on tests of vocabulary and serial 7's (which measure both information and working memory). Table 8 outlines the means, standard deviations and mean differences of the two groups on the different sub-domains. Given the significant difference in sample size and the unknown age range, caution must be taken in interpreting this data.

	HRS 2002	'Kiwi' ACE-R Pilot, 2011 N=45	Mean point difference
Immediate Recall (10 points)	5.51 (1.82) n=15051	5.91 (1.55)	0.40
Delayed Recall (10 points)	4.52, (2.17) n=15001	3.22 (1.96)	1.30
Total Recall (20 points)	10.05, (3.71) n=15001	9.13 (3.11)	0.92
Serial 7's subtraction (5 points)	3.67, (1.71) n=14698	4.91 (0.42)	1.24
Vocabulary (10 points)	5.66 (2.04) n=9423	7.82 (1.69)	2.16

Table 8: Mean Differences between the Current Sample and HRS Sample on Different Cognitive Tests

# Discussion

The aim of this study was to pilot the use of the modified Kiwi version of the ACE-R with community dwelling older New Zealanders.

The adapted 'Kiwi' ACE-R discriminated among different levels of cognitive functioning, (as evidenced by a good spread of scores), was easily understood by the participants, and correlated well with other measures of cognitive functioning. The internal consistency was slightly low compared to other studies that have used the measure (Hsieh et al., 2013; Mioshi et al., 2006b).

'Kiwi' ACE-R scores did not differ significantly from the control group in the original development paper. This suggests that; a) New Zealanders do not differ significantly from the United Kingdom controls, and b) adaptations to make this measure more acceptable for New Zealand participants did not negate the integrity of the measure. Within the sub-domains, New Zealand participants scored significantly lower in the visual-spatial domain. This discrepancy needs to be investigated further to see if this is a true difference in cognitive functioning in these populations, a result of cultural differences or unique to the population sampled. Investigating other norms of verbal fluency, language and visual-spatial skills in other countries and other

separate norms in New Zealand for equivalent tests may help with understanding the cross-nation discrepancies.

A few cautions are necessary when administering and scoring this measure. For example, in the naming sub-domain, interviewer judgement is required to ascertain the accuracy of these replies. Participants often named a barrel as a keg or named the crocodile/alligator as a lizard. Using the strict guidelines provided in the scoring manual, answers of 'keg' and 'lizard' would be scored as incorrect. However, keg is a more culturally accepted term in New Zealand, and it is impossible to judge size scale in these pictures (e.g., crocodile versus lizard), so these were both accepted as correct in the current study. These points may need to be elaborated on in the scoring criteria. In addition, when naming the rhinoceros some people called it a hippopotamus which may reflect a priming effect from a previous task (a task requiring the repetition of the 'hippopotamus') rather than any difficulty with naming items. Participants appeared to become quite confused when doing the three stage command, ("take paper in hand, fold it and put in on the floor") due to the unusual nature of the task. A discussion at the start of the assessment with the participants about being asked to do tasks that may seem easy, hard or strange,may help ease the administration of this item.

Interestingly, age was not correlated with cognitive functioning which is consistent with the original control group in which age had very little impact on scores, but inconsistent with the majority of research suggesting that cognitive function declines with age (Albert et al., 1993; Christensen et al., 1999; Cullum et al., 2000; Salthouse, 2002). This may be due to the restricted age range in this sample, with over half of the participant's ages within 10 years of each other, as was the case in the original control sample too.

Years of education had a significant impact on performance on the Malaysian version of the ACE (Mathuranath et al., 2007), which suggests that the ACE-R may be influenced by education. Educational experience needs to be routinely reported and explored to see whether or not it has a

potential moderating effect on ACE-R performance. This could be a potential source of spectrum bias. Within this sample education did not have an impact on 'Kiwi' ACE-R score. However, with over 60% of the sample having a post school qualification it is possible that there was not enough variability in qualification levels to show a significant difference in score.

There are a number of ways to define cognitive impairment and the lack of consensus around theoretical understandings of cognitive decline and the subsequent variations in measuring it, creates difficulty in deciding rates of impairments. The higher ACE-R pre-determined cut-off (<88) would overestimate the rate of impairment in New Zealand communities based on comparisons to other community research data (Bachman et al., 1992; Herzog & Wallace, 1997; Melzer et al., 1997). The alternative, more stringent, ACE-R cut-off (<82) is more likely to represent more accurate estimates of cognitive impairment in this sample.

There are a number of limitations in this study. The pilot study was conducted with people from the greater Wellington region in New Zealand and therefore the extent to which the sample is representative of the wider New Zealand population is unclear, reducing the ability for results to be generalized to all New Zealanders. Furthermore, this sample was comprised of volunteers who may not be representative of members of their generations. For example, volunteers are more often healthier, socially economically advantaged, intellectually able, well educated, confident and highly motivated (Ganguli, Lytle, Reynolds, & Dodge, 1998). Furthermore, the current sample were predominantly in the age group 65-75, ('young old') and therefore the results may only be generalizable to this age group. Cohort differences such as quality of childhood and lifetime nutrition, exposure to toxins or health hazards and education levels, work and lifestyles may also impact on scores. Due to the possible bias of participant selection, scores may present an elevated level of cognitive functioning than what would normally be expected. Collecting more extensive information about demographic factors and life course histories, and having a more representative sample of the population under investigation will improve the validity of findings and allow for more sophisticated data analyses.

# Conclusions

The adapted 'Kiwi' ACE-R represents a reliable and valid assessment tool for measuring multiple cognitive domains in non-clinical older adult community samples. Whilst some flexibility in the scoring criteria for naming, and consideration of priming effects need to be considered, overall it is a well-accepted measure. It is likely to add great value to research and primary health settings and aid in the early assessment of cognitive functioning in older adults.

# Competing interests: None

# **CHAPTER FOUR: INDIVIDUAL DIFFERENCES IN COGNITIVE AGEING**

The view that ageing is synonymous with universal and rapid cognitive decline is giving way due to recognition that for some people, mental acuity continues into advanced age (Padilla et al., 1992). Age-related changes in brain structure and function are not uniform across the whole brain or across individuals and neither are age-related changes in cognition uniform across all cognitive domains or across all older individuals. This indicates that inter-individual variation exists in both rate and severity of cognitive change. There are a myriad of factors that appear to attenuate the cognitive ageing process and may help predict when certain people may show decline. The next section explores the individual variations that influence cognitive functioning change.

There are many known factors that can increase or decrease the chances of developing cognitive impairment or sustaining good cognitive functioning. Factors that have been found to be predictive of changes in cognitive functioning are; manual social class (Cullum et al., 2000), visual and auditory acuity, socio-economic status (Huppert & Wilcock, 1997), depression (Bassuk, Berkman, & Wypij, 1998), genetics (Geda et al., 2006), health (Llewellyn, Lang, Langa, & Huppert, 2008a), strenuous activity and self-efficacy (Albert et al., 1993), gender (Rodgers, Ofstedal, & Herzog, 2003) and cognitive difficulties at time one of assessment (Huppert, Brayne, Gill, Paykd, & Beardsall, 1995).

In the MacArthur studies of positive ageing (Albert et al., 1993) the researchers used linear structural modelling to investigate demographic data and cognitive change from community based populations. Twenty-two different variables were examined including age, gender, race, income, education, alcohol, smoking, self-efficacy, physical markers, health markers, mental health, social ties, work and recreation. The studies found that education, strenuous activity, peak pulmonary expiratory flow rate and self-efficacy were direct predictors of cognitive change over the study period. Interestingly, age did not play a part in predicting cognitive functioning, possibly due to the restricted age range (aged 70-79). Education was the best predictor of cognitive change and

higher education levels were linked to income, gender and race. In a further study of multiple influences on cognitive change it was found that socio-economic status, gender and education all exerted independent effects on cognitive performance (Huppert et al., 1995).

In a large scale population-based longitudinal study, Cullum and colleagues (Cullum et al., 2000) found that for adults over 75 years of age there was a significant decline in cognitive scores over four years. Decline in the memory subscale was associated with less education, decline in attention was associated with manual social class and decline in perception was associated with older age. This is one of the few studies to investigate domain specific cognitive change longitudinally.

There are a number of explanations that may account for the impact of factors like these. For example, adaptive processes at neural, behavioural and social levels may mitigate the behavioural effects of neural changes and the socio-cultural environment may offer chances for adaptation and new growth (Padilla et al., 1992). These hypotheses go beyond the scope of this thesis. The more common factors that appear to influence the cognitive ageing process are explored in detail below.

# Age

Approaching old age is the strongest risk factor for cognitive impairment and decline, (Alexopoulos et al., 2007; Brayne, Gill, Paykel, Huppert, & O'Connor, 1995; Mungas et al., 2010). For example, dementia rises in prevalence from <1% of people aged <65 years, to an estimated 3–11% of those aged 65 years, and 33% of those aged 85 years. Cognitive impairment that is not part of the dementing process is even more common, with an estimated prevalence of around 17% or more in people aged 65 years and over (Graham, Rockwood, & Beattie, 1997; Hanninen et al., 1996; Low et al., 2004; Padoani et al., 1998; Plassman et al., 2008). These findings are supported by longitudinal studies that consistently find decreasing cognitive function with increasing age (Cullum et al., 2000; Hertzog, 2004).

The research strongly suggests that age is a huge contributor to cognitive decline, however, it is confounded by people who do not develop cognitive problems and by the large heterogeneity found within the rate and type of cognitive decline that occurs. One study that attempted to distinguish between ageing as the biggest factor and environmental effects, (which may be age related confounds) found that ageing had little impact on healthy people's mental status, (measured by the MMSE) over four years. Pervasive risk factors like hypertension and cardiovascular disease were more likely to explain any cognitive declines. (Starr, Deary, Inch, Cross, & MacLennan, 1997). In general the research suggests that age has a significant part to play in cognitive change, but what is unclear is whether other age related variables, (e.g. health, social participation and education) independently influence cognition or whether ageing and the associated brain change account for cognitive change.

### **Genetic influences**

It has been suggested that genetic influences account for 50% of the variance in adult cognitive abilities – much of this influencing the general factor of intelligence 'g', (Deary, Wright, Harris, Whalley, & Starr, 2004). The presence of the Apolipoprotein E (ApoE) genotype is a risk factor for late-onset dementia. This allele is associated with a faster rate of cognitive decline in non-demented individuals (Huppert et al., 1995) and people are more likely to suffer early death, cardiovascular disease, stroke and Alzheimer's dementia (Anstey & Christensen, 2000). This allele occurs in about 25% of the population and is associated with lowered cognition in non-demented older people in almost all studies (Anstey & Christensen, 2000).

## Activity

Growing evidence suggests that people who exercise at least once a week are less likely to experience cognitive decline than people who are not engaged in regular physical activity (Anstey & Christensen, 2000). In a large prospective study, higher levels of physical activity were associated with a reduction in cognitive decline, with more active and regular exercise having greater protective effects, (Albert et al., 1993). Mental activity or participating in mentally

stimulating events, (e.g., crosswords, reading books and magazines or playing cards) has also been associated with a lower risk of cognitive decline (Butler et al., 2004). These results are consistent with other research that shows weekly mental exercises improved cognitive and psychological well-being of patients with A.D. (Salthouse, 2006). The mechanisms associated with the improvement may be through improved brain activation, compensation or increasing neural networks by learning new information.

# **Social Support**

Social support plays a role in the attainment and maintenance of cognitive health. A lack of social engagement was found to be an independent risk factor for cognitive decline in older adults (Engelhardt et al., 2008). Social support modifies the relationship between measures of disease pathology, (e.g. neuro-fibrillary tangles) and level of cognitive health; therefore maintaining social networks could provide a protective effect against cognitive decline (Bennett et al., 2006). Close relationships offer cognitive stimulation via interaction and activity participation and helps the development and use of compensatory mechanisms.

# Education

Educational history plays a consistent role in predicting cognitive change, with higher levels of education associated with greater maintenance of cognitive skills, (Christensen et al., 1999; Cullum et al., 2000). Indirect evidence comes from studies showing positive correlations between years of education and less decline in cognitive abilities in later decades (Powell & Whitlia, 1994). There are a number of reasons formulated for these findings. Education may have direct effects on brain structure early in the life span which may help delay the appearance of clinical symptoms, (e.g., reserve capacity Tuokko et al., 2003), or education may be a surrogate for environmental experiences that have an impact on cognition, (e.g., illness, health habits, higher socio-economic status, better access to medical care and other health enhancing activities, Powell & Whitlia, 1994). It is also possible that more highly educated people are more used to tests and testing situations and therefore perform better.

#### **Physical health**

A number of researchers have shown that conditions that are associated with ageing, that are not specifically considered cognitive pathology, (e.g., sensory decline or cardiovascular problems) can manifest cognitive difficulties (Christensen, 2001; Huppert & Wilcock, 1997; Thorgrimsen et al., 2003). For example, having a cardio vascular attack (CVA) predicted increased risk of cognitive decline (Christensen, 2001). In support of this some medications have been shown to help protect against cognitive decline, including; oestrogens in women, anti-inflammatory medication and vitamin E (Huppert et al., 1995); however, the mechanisms are unclear. It has also been suggested that visual and auditory acuity, arthritis and balance can be markers for age-related differences in mental competence due to changes in the central nervous system (Rabbitt et al., 2001).

Other research suggests that less than 2% of variance in cognitive score was due to number of physical symptoms (Powell & Whitlia, 1994) and that 15-20% of age-related variance in cognitive score was accounted for by self-rated health – specifically, subjective rather than objective measures of health (Salthouse, 1994). Salthouse claimed that there is little evidence that declines in cognitive performance, associated with increased age, are mediated by declines in health status (Salthouse, 1994). In a summary of longitudinal studies (Anstey & Christensen, 2000), three studies found no relationship between self-reported poor health and cognitive change whereas two studies did, with low ratings being associated with greater change and more objective measures of health status related to cognitive decline.

The relationship between physical health problems and cognition is still unclear. Physical health may be associated with other lifestyle factors such as diet or genetics which can play a role in cognition. Or it is possible that it is the individual's interpretation of the impact of physical health that impacts cognitive functioning. One way to explain the differences in studies is through the difference in use of subjective and objective measures, with objective measures appearing to be more sensitive to deficits than subjective measures. Additionally, many 'normative' studies of cognitive functioning leave out people who have had strokes, brain tumours, head injuries, diabetes or thyroid difficulties making it difficult to establish the impact of health status on cognition.

# **Emotional health**

A number of studies have found that depressive symptoms are associated with poorer cognitive functioning performance (Bunce, Batterham, Mackinnon, & Christensen, 2012; Elderkin-Thompson et al., 2003; La Rue et al., 1995; Lichtenberg, Ross, Millis, & Manning, 1995; van den Kommer et al., 2012), and a higher risk of cognitive decline (Paterniti, Verdier-Taillefer, Dufouil, & Alperovitch, 2002a). Longitudinal studies have shown an association between depressive symptoms at baseline predicting decline of cognitive functioning, (particularly information processing speed), independent of covariates (van den Kommer et al., 2012). Multiple regression analyses, controlling for the direct effects of demographic factors, found that the Geriatric Depression Scale (GDS) was a significant consistent predictor of the Dementia Rating Scale and Logical Memory scores. Overall, GDS scores accounted for approximately 8% of unique variance for both measures of cognition (Lichtenberg et al., 1995). Higher depression symptom scores have been associated with poorer initial performance in processing speed, verbal fluency and episodic memory (Bunce et al., 2012). When those with cognitive deficits at baseline (e.g., diagnosed with mild cognitive impairment or dementia) are removed from analysis, these associations became non-significant, suggesting that depression-related cognitive deficits represent a prodromal or risk factor for Dementia (Bunce et al., 2012). Reasons for this relationship are varied: depression may precede a cognitive decline, older people may become despondent at minor lapses in cognitive skills and believe these are precursors of dementia and depression may develop in response to these assumptions resulting in less effort to remain mentally active (Bassuk et al., 1998).

Higher levels of anxiety are associated with difficulties with concentration, working memory and processing information, (Hertzog, Van Alstine, Usala, Hultsch, & Dixon, 1990). Bierman and colleagues (2005b) found main effects of anxiety symptoms on learning and delayed recall of word list tasks; with mild anxiety symptoms associated with better cognitive performance, whereas severe anxiety symptoms were negatively associated with cognitive functioning. These researchers suggested that anxiety has a curvilinear relationship with cognition. In another study, Bunce et al., (2012) found that after removing cases of MCI or dementia from regression models, associations between the cognitive variables and anxiety symptoms strengthened, consistent with the possibility that associations between anxiety and cognition may be more characteristic of normal aging.

# Summary

There appear to be a number of factors that influence cognitive functioning directly and indirectly. Not only are there biological and genetic factors to contend with, but also the impact of choices we make during our lives. The unique contribution of some of these factors on cognitive functioning will be explored in a nationally representative cross-section of older New Zealanders. What follows is a manuscript prepared for publication that uses the ACE-R in a large population based sample and investigates some of the important factors that influences cognitive functioning.

# Study Two: Normative data for older New Zealanders on the Addenbrooke's Cognitive Examination-Revised and the influence of demographic variables.

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#### Abstract

The purpose of cognitive screening tests is to specify the likelihood of actual cognitive impairment, inferred from the association of the person's score to reference norms. New Zealand is following the trend of developing test norms for cognitive tests for use with older people. Normative data, obtained from a nationwide (population based) sample of 1005 New Zealanders, 45 to 85 years of age, are presented for the Addenbrooke's Cognitive Examination-Revised (ACE-R), a screening measure of cognitive ability. The norms are presented for different age groups, sex, New Zealand European and Māori ethnicity and educational bands.

# Introduction

To best understand data derived from assessments, a reference point to what constitutes 'normal' performance is required. This frame of reference is provided by normative data which gives the empirical context and represents the range of performances on a particular test. Normative reference groups are considered the 'gold standard' against which an individual's test performance is compared and contrasted (Feigin & Barker-Collo, 2007).

Unfortunately, many tests which are used have a limited range of norms, often excluding those age groups where cognitive decline may begin to occur (Siegert & Cavana, 1997). Lezak (1987) reviewed the ten most commonly used American tests and found that adequate age norms for older people were virtually non-existent. More recently, there has been a concerted effort to collect population-based test norms for older people. For example, the Mayo clinic (Mayo's Older American Normative Studies, MOANS) has developed normative data for Americans aged 55-97 for fifteen different neuropsychological tests measuring many different cognitive functions

(Roberts et al., 2009). There have been attempts to develop age appropriate norms suitable for older New Zealanders on neuropsychological tests with norms developed for: the Rivermead Behavioural Memory Test (Fraser, Glass, & Leathem, 1999), Trail Making Test (Siegert & Cavana, 1997), Rey Auditory Verbal Learning Test (Newlove, 1992), Controlled Oral Word Association Test, Graded Naming Test and the Recognition Memory Test (Harvey & Siegert, 1999). These norms are appropriate for a wide range of older age groups and specific to the New Zealand population.

Results become even more meaningful and accurate when compared to others with as many similar characteristics as possible, (e.g., cultural background, education, age, sex etc). For example, more variance in cognitive assessment scores is found within older age groups; i.e., the older people get, the more heterogeneous their scores become (Hanninen et al., 1996). Education level also impacts on cognitive ability in tests. For example, higher education levels have been associated with reduced variability in cognitive scores over time and a decreased risk in developing cognitive impairments (Christensen et al., 1999). Some cognitive tests take this into consideration by offering a conversion score that takes years of education into account, (e.g., the Montreal Cognitive Assessment, Nasreddine et al., 2005). There are a number of mechanisms that may explain lower rates of cognitive decline in older people with higher levels of education. First, people with lower education may be at more risk of central nervous system damage (e.g., through illness, poor living conditions or dietary deficiency), (Leibovici, Ritchie, Ledésert, & Touchon, 1996); second, people with higher education may have greater neuronal reserve capacity or integrity and/or reduced risk of neuronal damage (Christensen, 2001; Valenzuela & Sachdev, 2006); thirdly, people with higher levels of education may be better able to generate compensatory strategies (Leibovici et al., 1996) and finally, it is possible that people with higher levels of education may be better at doing paper and pen tests which affords them a higher chance of performing well. Research amongst these hypotheses is limited. However, one study that analysed these found that people with higher levels of education appear to show greater resistance to change on tests with a high learned component (e.g., tests of language and secondary memory) and that "cognitive functions such as attention, implicit memory and visual-spatial analysis, (which might be postulated to have a higher 'nature' rather than 'nurture' component), level of education are relatively unaffected by level of education (Leibovici et al., 1996, p. 396). This is suggestive that higher education is associated with a better ability to continue developing verbal cognitive skills in spite of deterioration in other areas. This research highlights the need to take education into account when looking at cognitive scores and also to have tests that show subdomain skills (rather than a global score) due to the possibility that deterioration in other domains may be masked by higher verbal and memory skills.

These demographic issues raise concerns about normative data developed in other countries. For example, the National Adult Reading Test (NART) is based on word pronunciation and was originally developed and standardized on a British population (Nelson, 1991). Scores on this test are based on British pronunciation and familiarity with words such as "drachm"<sup>4</sup>, this represents a challenge to people unfamiliar with British language and may unduly influence a person's score (Harvey & Siegert, 1999). Western-based tests used across different cultures may not meet the requirement for a standardised assessment, with those of other cultures possibly being unfairly disadvantaged and over-diagnosed (e.g., false-positives).

Interpretation of assessment results from New Zealanders, using non-New Zealand norms, may be an inaccurate representation of that person's ability. For example, by virtue of residing in this country, older people have been exposed to different cultural and life experiences, health care, political and social welfare systems to people in other countries. According to the 2008 Dementia Manifesto (Alzheimers New Zealand, 2008), the on-going collection of population-based data is necessary in order to maximise cross-cultural validity. New Zealand has a diverse population comprised of many ethnicities and cultures and as such differs on many socio-demographic, cultural and societal factors compared to normative reference groups from other western countries

<sup>&</sup>lt;sup>4</sup> Drachm is a unit of weight formerly used by apothecaries, equivalent to 60 grains or one eighth of an ounce.

(Guenole, Englert, & Taylor, 2003; Ogden & McFarlane-Nathan, 1997b). Using cognitive assessments without appropriate culturally relevant adaptations, and applying norms derived largely from the western population, has resulted in the overestimation of cognitive impairment in the local populations of developing regions (Mathuranath et al., 2007) and New Zealand groups (Harvey & Siegert, 1999).

To illustrate the substantial cross-country differences can have on cognitive scores, Table 9 summarises mean scores of the Addenbrooke's Cognitive Examination-Revised, (ACE-R, Mioshi et al., 2006a) when used in different countries. The ACE-R is the third most commonly used cognitive screening test in New Zealand (Strauss et al., 2012). The studies shown compared a clinical sample to a control group – the non-impaired norm.

Table 9: Cross-Country ACE-R Score Difference in Control Group Participants

Country	Control Group	ACE-R	Mean Age (SD)	Education (years)
	(N)	Mean score		
United Ki	ingdom 63	93.7 (4.3)	64.4 (5.7)	12.7 (2.1)
Greece	60	89.1 (7.5)	66.0 (8.9)	10.6 (4.2)
India	135	83.4 (7.2)	68.5 (7.1)	7.90 (5.4)
Japan	62	88.1 (4.3)	66.7 (10.1)	12.3 (3.6)
Spain	32	79.9 (7.6)	74.5 (5.4)	10.9 (1.4)
Korea	84	80.7 (6.0)	67.8 (9.3)	10.1 (4.1)

*Note:* United Kingdom, (Mioshi et al., 2006a), Greece Konstantinopoulou et al. (2010), India (Mathuranath et al., 2006), Japan (Slawek, Derejko, & Lass, 2005), Spain (Garcia-Caballero et al., 2006), Korea (Banerjee et al., 2006).

According to the cut-off scores proposed in the original ACE-R article (Mioshi et al., 2006a), four of these countries' 'normative' samples, (i.e., control groups) would meet criteria for cognitive impairment, including dementia. These findings show the importance of developing specific country norms and cut offs for screening for cognitive impairment which take into account cultural differences and language barriers between countries. It is also possible that these differences exist within the same country. For example, in Auckland, New Zealand, 56.5% of its population identify with the European ethnic group, 18.9 percent with the Māori ethnic group, 14.4 percent with the Pacific peoples ethnic group, and 11.1 percent with the Māori ethnic group

(Statistics New Zealand, 2012). Ethnicity is a measure of cultural affiliation and thus reflects the diverse range of cultures and backgrounds in New Zealand. Another factor that may have influenced the differences between samples in Table 9 is educational level. The control group from the original article (Mioshi et al., 2006a) was highly educated compared to most other samples. These studies highlight the need for assessments to use appropriately normed reference groups when interpreting individual test scores. Ideally, norms should be developed that match for age, education and ethnicity.

The influence of cultural variation has received little attention in the literature in terms of the validity of psychometric testing, even though researchers agree that validity can be compromised when this is not taken into account and that ethnicity and culture do affect test scores (Lezak, Howieson, & Loring, 2004; Rosselli & Ardila, 2003). Efforts to examine the influence of culture on cognitive functioning scores have found that New Zealand samples perform lower than normative data would anticipate. For example, the California Verbal Learning Test norms (based on U.S. samples) placed healthy New Zealand participants, (aged 17 to 81 years) in the 16<sup>th</sup> percentile (Barker-Collo, Clarkson, Cribb, & Grogan, 2002). In a naming test, (Boston Naming Test) university students based in New Zealand made up to 60% more errors than the American normed population; errors were made on naming items such as pretzel, beaver, globe, funnel and tripod (Barker-Collo, 2001). In an unpublished study of community based New Zealander's, (aged from 25 to 65+ years), participants had significantly lower scores on the Montreal Cognitive Assessment compared to the original population (Sothieson, 2010). Results of these studies suggest that New Zealanders would obtain lower scores on the ACE-R as well. This was not the case in the previous pilot study of the New Zealand version of the ACE-R and older adults, a result which requires replication.

Lower scores in comparison to normative samples are likely to result in a larger proportion of New Zealanders being spuriously identified as having deficits (Feigin & Barker-Collo, 2007). One option to counteract these differences is to develop assessments that are more sensitive to our unique population and culture. For example, in the study cited above (Barker-Collo, 2001), New

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Zealander's improved their scores considerably when using a New Zealand adapted measure of verbal fluency. Differences in cognitive functioning scores across countries emphasises the need to increase the validity of assessment by using measures that are appropriate to the context and population they are being used with .

Ethnic variation is found within New Zealand on performance in neuropsychological tests; with Māori participants performing significantly lower than European participants (Ogden & McFarlane-Nathan, 1997b). A person of Māori descent who sustains a head injury, and is assessed with neuropsychology tests developed and normed in the UK or the USA, can show impairments that are more to do with cultural bias of the tests than any effects of brain damage (Ogden, 2001). This is not surprising, given that most standard measures are based on Western schooling and assumptions that favour those from "Western" backgrounds, (Rosselli & Ardila, 2003). When cognitive assessments have been translated into Te Reo for Māori speakers, Māori participants show performances that are equal or better than European participants (Ogden & McFarlane-Nathan, 1997b). This emphasizes the need for New Zealand-based norms in order to create valid assessment and accurate diagnosis for unique population groups.

# Summary

When making decisions about an individual's cognitive abilities it is vital to compare them to a similarly matched reference group to avoid biases impacting on interpretation of scores. Research generally shows that there are significant differences in scores cross-country and cross-culturally. To improve validity of assessment, these measures need to be appropriate to the context and population they are being used with, (Barker-Collo, 2001; Barker-Collo et al., 2002; Feigin & Barker-Collo, 2007). The inclusion in longitudinal large scale health studies of valid and reliable cognitive assessment tools, that have been normed specifically for New Zealand older adults, will provide more accurate assessment and more valid interpretation of test results.

# Method

#### **Participants**

The current sample of 1005 participants was drawn from a population sample collected as part of the New Zealand Longitudinal Study of Ageing (NZLSA). NZLSA expands on the earlier Health, Work and Retirement study (HWR) which recruited a representative sample of older New Zealanders from the New Zealand electoral roll in 2006 aged 55 to 70 years. In 2010 the sample was expanded to include younger and older age groups (ranging from 45-84) and became the New Zealand Longitudinal Study of Ageing (NZLSA); a population-level study. The NZLSA had two specific objectives: (1) to establish a nationally representative longitudinal study of the health, wealth and social factors that contribute to positive ageing in New Zealand, and (2) to compare the data gathered with that of similar studies in Australia, UK, the USA and Europe in order to best inform public policy and practice from an international perspective. The specific aims of NZLSA are to make observations and test hypotheses about the contributions to ageing people's quality of life within four broad areas: Economic participation (e.g. meaning of work, employment, retirement); Social participation (e.g. family support, social capital, civic participation); intergenerational transfers (e.g. family care, income, wealth and knowledge); resilience and health (e.g. control, coping, physical, emotional, cognitive).

A total pool of 4,339 older New Zealanders were invited to participate in the first NZLSA postal data collection wave in 2010, and comprised (1) HWR participants who participated in the 2008 data collection wave, (2) HWR participants from 2006 who consented to re-enter the study, (3) participants from a related cross-sectional study of retirement planning at Massey University, (4) participants from a pilot study conducted on the NZLSA survey questionnaire, and (5) New Zealanders randomly selected from the New Zealand Electoral Roll to increase the numbers of respondents at the younger (i.e., 45-54) and older (i.e., 70-84) age groups. These groups were sampled using the same sampling frame used in the New Zealand electoral roll. Māori oversampling was specifically undertaken during participant selection for NZLSA. A total of 3,312 (76%) from the pool completed NZLSA Wave 1 questionnaires (2010). For more details of the original sampling procedure see Alpass et al., (2007).

The current sample was recruited through the NZLSA database from people who volunteered to have face to face interviews. The present sample study is comprised of 1005 participants; 47.6% male and 52.4% female. Age ranged from 48-83 years<sup>5</sup> with a mean age of 61.9 (SD 7.79). Participants were grouped into four age brackets for normative purposes. Those above 75 years and over (n= 105), those aged from 65 to 74 years (n=105), those aged from 55 to 64 years (n=369) and those aged below 55 years (n=298). A large percentage were well educated, having either tertiary education (n= 222, 22.1%) or at least post-secondary or trade qualifications (n=366, 36.4%). Over half the sample were married (n=630, 62.6%) and the majority of the sample described themselves as New Zealand European (n=883, 87.8%). Table 10 compares the participants' demographic data with that of the census data from 2006.

<sup>&</sup>lt;sup>5</sup> The sampling frame was designed to recruit 50 to 84 year olds. Due to the nature of the New Zealand electoral roll which only includes year of birth and not date of birth, and the date of recruitment (May 2010), a number of participants aged aged less than 50 years were also included in the sample.

· · · · · · · · · · · · · · · · · · ·	% NZLSA sample aged 48-84, N=1005	% General population (2006) aged 45-84, N=1,453,194,
Sex		
Male	45.6	47.6
Female	54.1	52.3
Age		
45-54	29.7	38.4
55-64	36.8	30.0
65-74	22.9	19.4
75-84	10.6	12.2
Primary Ethnic Group Affiliation		
Pakeha/New Zealander or European	86.2	71.1
Māori	7.6	7.6
Pacific Island	0.6	3.2
Asian	1.9	5.5
Other	3.7	12.6
Marital Status		
Married	63.4	59.9
Civil Union/De facto	6.9	-
Same Sex Civil Union/De Facto	1.5	-
Divorced/Separated	11.1	14.9
Widow or Widower	11.0	11.7
Single	5.7	7.2
Missing	-	6.3
Highest Qualification		
No Qualifications	17.4	37.2
Secondary School	22.4	27.9
Post-Secondary /trade	36.4	25.4
University Degree	22.1	10.0

Table 10: Characteristics of NZLSA Weighted Face To Face Study Population Compared to General Population Using Census Data From 2006

The current sample represents 0.05% of the total New Zealand population aged over 45 years. HWR and NZLSA over-sampled for Māori and a post-stratified weighting variable was calculated to account for known discrepancies between the sample and the population. Compared to the general population aged over 45, the current sample that volunteered were more highly educated, under-sampled in the 45-54 age group and 75+ age group and had a greater proportion of people in the 55-64 and 65-74 age groups. Pacific Peoples and Asian ethnic groups were under represented. Overall this sub-group is generally representative of the targeted population and norms generated from this sample are likely to be representative of older New Zealanders.

#### Procedure

Face-to-face interviews were conducted nationwide with a voluntary subset of the 2010 postal survey responders (N=1005) who resided independently in the community. Participants were interviewed in their own home. Interviewers were given specific training in administering questionnaires and tests, with adherence to test manual instructions. The author was not an interviewer.

## Materials

Participants completed the 'Kiwi' ACE-R as part of a battery of scales and items used in the faceto-face interview. Other measures included questions relating to demographics, income and assets, future housing intentions, depression symptoms and anxiety symptoms. Interviews took around one hour to complete. For the purposes of the present study, only demographic and cognitive functioning measures are described.

# Addenbrooke's Cognitive Examination Revised (ACE-R, Mioshi et al., 2006a).

The ACE-R is a cognitive screening measure for dementia. It was developed originally in 2000 (Mathuranath et al., 2000), and revised in 2006 (Mioshi et al., 2006a), as an improvement on the Mini Mental State Examination (MMSE, Folstein et al., 1975) with lower ceiling effects (expanding the points available), improved sensitivity, and assessment of more cognitive domains, particularly components for memory and frontal/executive functioning (Mathuranath et al., 2000). Extra non-MMSE items improve estimates of cognitive ability by 16% compared to the MMSE (Law, Connelly, Randall, 2012). The ACE-R was developed and normed in the United Kingdom and includesnorms for clinical and non-clinical populations. The ACE-R has good psychometric properties, with very good internal consistency, ( $\alpha$ =0.80) and significant concurrent validity, (as measured by the correlation coefficient between the ACE-R and the Clinical Dementia Rating Scale, -0.32). No significant age or education effect on scores were found (Mioshi et al., 2006a).

The measure includes items assessing the cognitive domains of: attention and orientation (e.g., what is the date?), fluency (e.g., naming words beginning with F), language (e.g., writing sentences and repeating words), visual-spatial (e.g., copying a pentagon and drawing a clock face) and memory (e.g., short term, long term, anterograde and retrograde tasks). There are a total of 100 points available across the five domains and it takes 10-15 minutes to administer.

In the past decade the ACE-R has been cited as a potentially useful screening tool in guideline documents by the National Institute for Health and Clinical Excellence (2006). It has been used in one community-based longitudinal study, (Larner, 2009) with adults (aged 24 to 85 years) who were recruited from a cognitive function clinic in the United Kingdom. The ACE-R showed value in repeat testing over a 6-46 month period and was sensitive to cognitive decline, stability and improvement. It was deemed a good measure for cross-sectional and longitudinal assessment of cognitive disorders. Community norms have also been developed in a cross-sectional study with healthy adult volunteers (aged 50-85 years), residing in Brazil, (Amaral-Carvalho & Caramelli, 2012). The study found that years of education affected all ACE-R subs-cores andage influenced the verbal fluency sub-score and the ACE-R total score. Sex affected the attention and orientation and MMSE sub-scores, but not the ACE-R total score. These studies suggest that the ACE-R has potential use in large community based and longitudinal studies and that age, education and sex need to be considered in the analysis of results.

The ACE-R has been modified for use with New Zealanders, (the 'Kiwi' ACE-R; Taylor, 2008) and permission was obtained from the developers to use the modified version in the NZLSA face-to-face interviews. In accordance with suggestions from the developers, more site specific anterograde, retrograde and delayed recall memory components were modified to make the ACE-R more culturally acceptable. For example, using a New Zealand address in memory tasks and recalling the current New Zealand Prime Minister rather than the United States of America President Other countries have followed these suggested guideline changes and have found little

change to the psychometric properties of the measure (Alexopoulos et al., 2007; Garcia-Caballero et al., 2006; Konstantinopoulou et al., 2010).

#### Supplementary cognitive measures

To allow for cross-country comparisons, further cognitive measures used in a large representative longitudinal study in the United States, the Health and Retirement Study (HRS), were included in the NZLSA face-to-face interviews. The questions include items from existing measures, the Weschler Intelligence Scale-Revised (WAIS-R, Wechsler, 1981) and the Telephone Interview for Cognitive Status (TICS, Brandt et al., 1988). They include items that assess memory, (e.g., immediate, delayed and working), mental status, (e.g., knowledge, language and orientation), abstract reasoning, (e.g., similarities subtest), vocabulary, (e.g., definitions) and numeracy, (e.g., math problems). Results from the HRS sample are publicly available and allow for cross-nation comparisons of cognitive ability on these items.

## Results

#### Data analyses.

All statistical analyses were conducted using the Statistical Package for Social Sciences, SPSS (version 20.0, Chicago, IL). Pearson's correlations were used to assess the direction and strength between variables. Student T-tests and Analysis of Variance (ANOVA) were used to test for differences between groups, and where significant, post-hoc analyses were used to explore differences between sub groups. Effect sizes were calculated using  $\eta^2$  or Cohen's *d*.

# 'Kiwi' ACE-R Scores.

Scores on the 'Kiwi' ACE-R ranged from 56-100. The mean was 93.65 and the standard deviation (SD) was 5.10. The total ACE-R score in this sample did not differ significantly from the original normed sample (M=93.7, SD=4.30), t (1066) = -0.07, p<0.94, or on any of the sub-domains. Table 11 shows a summary of the ACE-R total score and sub-domain scores.

Table II. KIWI MCL-K IU	Table 11. Kiwi MCL-K Total and Sub-Domain Scoles (II-1005)							
Domain (points available)	Minimum	Maximum	Mean (SD)					
ACE-R total (100)	56	100	93.65 (5.10)					
Attention/Orientation (18)	12	18	17.85 (0.52)					
Memory (26)	5	26	23.89 (2.46)					
Verbal Fluency (14)	0	14	11.55 (2.06)					
Language (26)	14	26	24.95 (1.57)					
Visual-spatial (16)	10	16	15.39 (0.97)					

Table 11: 'Kiwi' ACE-R Total and Sub-Domain Scores (n=1005)

# Normality.

'Kiwi' ACE-R scores, for the current sample, approximate a normal distribution curve. Figure 2 shows that the data is highly negatively skewed (skew, -1.99) with a leptokurtic distribution showing a high central peak and long tails (kurtosis, 7.27). This was expected as the 'Kiwi' ACE-R was developed as a screening test for cognitive impairment which only affects a minority of the population. Thus, the 'normal' population would be expected to perform highly on this measure.

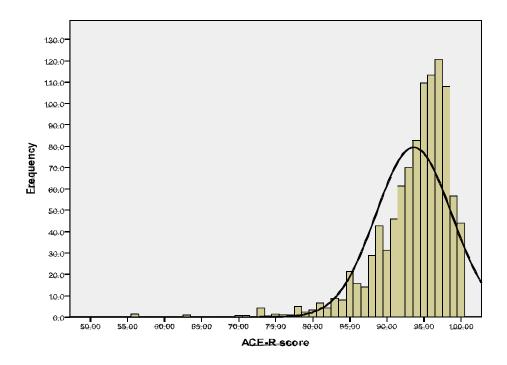


Figure 2: Distribution of 'Kiwi'ACE-R Scores Showing Normal Distribution Curve for the normative group.

#### Reliability and validity.

The Chronbach's alpha measuring internal consistency was  $\alpha = 0.70$ . Alpha was derived from totals of sub-domain items (n=26). Total 'Kiwi' ACE-R score correlated highly with all of the sub-domains; Pearson correlations are shown in Table 12.

Table 12: Pearson's Correlations (R) of the 'Kiwi'	ACE-R Total and Sub-Domain Scores.
--	------------------------------------

	'Kiwi'	Attention/	Memory	Verbal Fluency	Language	Visual-spatial
	ACE-R	Orientation				
ACE-R	1	$0.38^{**}$	$0.77^{**}$	$0.70^{**}$	$0.71^{**}$	$0.44^{**}$
Attention/ Orientation	1	1	$0.21^{**}$	$0.17^{**}$	$0.28^{**}$	$0.10^{**}$
Memory			1	$0.28^{**}$	$0.40^{**}$	$0.19^{**}$
Verbal Fluency				1	$0.35^{**}$	$0.20^{**}$
Language					1	$0.22^{**}$
Visual-spatial						1

\*\* Correlation is significant at p<0.00

Concurrent validity was assessed through Pearson correlations with other cognitive tasks included in the interviews. Total 'Kiwi' ACE-R scores in this sample correlated significantly with most other cognitive tasks: MMSE (r=0.67, p<0.00) (embedded in the 'Kiwi' ACE-R), Free Recall (r=0.50, p<0.00) (TICS), Delayed Recall (r=0.52, p<0.00) (TICS), Numeracy (r= 0.37, p<0.00 (adapted from Lipkus, Samsa, and Rimer [2001], see Ofstedal et al., 2005 for more detail), Word Similarity (r=0.46, p<0.00) (WAIS-R) and Word Meaning (r=0.47, p<0.00) (WAIS-R). These results are suggestive of good concurrent validity. No other studies have researched the association of the 'Kiwi' ACE-R with non-dementia related cognitive scales.

# Normative data stratified by significant demographic variables.

The 'Kiwi' ACE-R showed significant associations with the demographic variables, age, education, ethnicity and sex. Thus norms are provided for each of these demographic parameters.

Age. One way ANOVA showed a main effect for age on 'Kiwi' ACE-R scores, F (3, 951) = 36.58; p<.00,  $\eta^2$  =0.10, (medium effect). Post hoc comparisons using the Tamahane's 2 (unequal variances) test indicated that older age groups had significantly lower scores than younger age groups. The largest mean difference was -5.12 which was between the two age groups <55 and 75+. Significant differences between the age groups also occurred within the subdomains when the age gap was at least ten years (except in the attention/orientation domain). The mean scores for the four different age groups are given in Table 13. Age remained significant when education, gender and ethnicity were controlled, [F (6, 932) = 33.13, p<.00,  $\eta^2 = 0.17$ ], suggesting it would be appropriate to provide norms by age group.

		JSS FOUL Age C	1				
Age Group	Ν	'Kiwi'	Attention/	Memory	Verbal Fluency	Language	Visual-spatial
(confidence		ACE-R	Orientation				
interval)							
45-85	10016	93.65 (5.10)	17.85 (0.52)	23.89 (2.46)	11.55 (2.06)	24.95 (1.57)	15.39 (0.97)
95 % CI		93.33-93.96	17.82-17.88	23.74-24.04	11.42-11.67	24.85-25.04	15.33- 15.45
<55	298	95.01 (4.02)	17.91 (0.35)	24.19 (2.10)	12.10 (1.84)	25.27 (1.31)	15.59 (0.83)
95% CI		94.53-95.48	17.87-17.95	23.91-24.39	11.89-12.30	25.10-25.40	15.48-15.67
55-64	368	04 42 (4 27)	17.87 (0.36)	24 20 (2 21)	11.70 (1.90)	25.11 (1.36)	15.50 (0.82)
	308	94.42 (4.27)	· · ·	24.30 (2.21)		· · · ·	· · ·
95% CI		93.99-94.86	17.84-17.91	24.04-24.49	11.50-11.89	24.94-25.23	15.40-15.57
65-74	230	92.34 (6.04)	17.76 (0.81)	23.53 (2.81)	11.08 (2.27)	24.79 (1.55)	15.15 (1.14)
95% CI		91.55-93.12	17.65- 17.87	23.17-23.89	10.79-11.39	24.56-25.98	15.02-15.32
75+	105	90.12 (5.67)	17.85 (0.38)	22.59 (2.81)	10.43 (1.96)	24.09 (2.02)	14.97 (1.19)
95% CI		89.03-91.21	17.77-17.93	22.14-23.22	10.06-10.86	23.75-24.49	14.76-15.22

Table 13: Weighted Mean Scores (Standard Deviation) on Total 'Kiwi' ACE-R and 5 Domain Sub-Scales Across Four Age Groups

Figure 3 shows 'Kiwi' ACE-R domain performance based on age group. Due to uneven number of tasks within each sub-domain, scores for each sub-domain have been standardized using a Z-score.

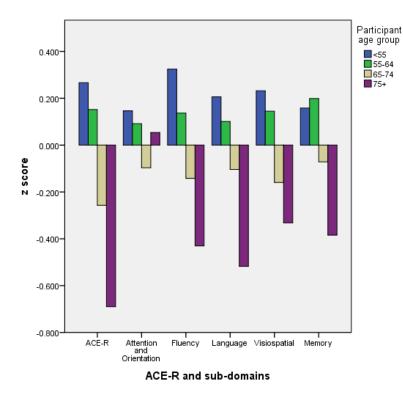


Figure 3: Standardized 'Kiwi' ACE-R and Domain Score for Different Age Groups.

<sup>&</sup>lt;sup>6</sup> Lower N is due to missing data for age group (i.e., data for participant age is missing for four participants).

*Education*. Analysis of variance showed a significant main effect for education level on 'Kiwi' ACE-R score, F (3, 937) = 31.28, p=<.00,  $\eta^2$ =0.09 (medium effect). Post hoc analyses using Tamahane's 2 (unequal variances) test showed that people with tertiary qualifications had significantly higher 'Kiwi' ACE-R scores (M= 95.3, SD=4.8) than all other levels of education; post-secondary/trade (M= 94.1, SD=4.3), secondary school (M=93.5, SD=4.6) and no qualifications (M= 90.0, SD=6.0). The largest mean difference was between tertiary and no qualifications (Mean difference= 4.64). No significant differences were found between post-secondary/trade qualifications and secondary school qualifications. When age, ethnicity and sex were controlled for education remained significant [F (6, 932) = 32.16, p<.00,  $\eta^2$ = 0.17). Table 14 shows the mean and standard deviation for each education group, across 'Kiwi' ACE-R domains and Figure 4 shows this with age groups collapsed.

Education Level	N	'Kiwi' ACE-R	Attention/ Orientation	Memory	Verbal Fluency	Language	Visual-spatial
No qualifications							
45-85	175	90.92 (6.13)	17.69 (0.71)	23.02 (2.95)	10.68 (2.21)	24.35 (2.05)	15.16 (1.21)
95% CI		90.01-91.83	17.58-17.80	22.58-23.46	10.35-11.01	24.04-24.65	14.98-15.34
<55	34	93.54 (5.74)	17.74 (0.61)	23.76 (2.05)	11.59 (2.29)	24.69 (2.35)	15.76 (0.43)
55-64	61	92.54 (1.56)	17.81 (0.46)	23.35 (3.19)	11.15 (1.59)	24.71 (1.46)	15.49 (0.89)
65-74	56	88.91 (6.63)	17.61 (0.95)	22.55 (3.01)	9.77 (2.58)	24.29 (1.85)	14.68 (0.19)
75+	23	88.05 (6.59)	17.56 (0.73)	22.26 (3.19)	10.19 (1.70)	23.52 (2.59)	14.49 (1.37)
Secondary school							
45-85	225	93.61 (4.97)	17.88 (0.37)	23.97 (2.45)	11.42 (2.02)	24.93 (1.75)	15.39 (0.92)
95% CI		92.96094.26	17.83-17.93	23.65-24.29	11.15-11.68	24.70-25.15	15.27-15.51
<55	69	93.54 (5.74)	17.91 (0.33)	24.82 (1.51)	11.81 (2.19)	25.35 (1.32)	15.59 (0.78)
55-64	78	92.98 (5.43)	17.85 (0.39)	23.90 (2.32)	11.18 (2.20)	24.64 (2.18)	15.36 (0.98)
65-74	57	93.65 (4.09)	17.87 (0.41)	23.83 (2.76)	11.57 (1.54)	25.06 (1.14)	15.31 (0.89)
75+	22	89.84 (5.50)	17.91 (0.28)	21.83 (3.07)	10.67 (1.68)	24.29 (2.23)	15.13 (1.11)
Post-secondary /trade 45-85	e						
95% CI	336	94.15 (4.11)	17.90 (0.37)	24.11 (2.25)	11.64 (1.96)	25.07 (1.25)	15.41 (0.91)
<i>) ) i i i</i>	550	93.73-94.57	17.86-17.94	23.88-24.34	11.43-11.84	24.94-25.20	15.31-15.50
<55		20110 2 1107	17.00 17.91	25.00 2 1.5 1	11.10 11.01	21.91 20.20	10.01 10.00
55-64	95	94.38 (4.11)	17.94 (0.22)	24.06 (2.55)	11.79 (1.52)	25.14 (1.32)	15.58 (0.67)
65-74	162	94.92 (3.52)	17.88 (0.40)	24.49 (1.84)	11.82 (1.91)	25.23 (1.08)	15.46 (0.79)
75+	74	93.38 (4.71)	17.87 (0.49)	23.86 (2.39)	11.39 (2.31)	24.97 (1.27)	15.26 (1.08)
	35	91.58 (4.17)	17.56 (0.73)	23.48 (2.60)	10.86 (2.24)	24.33 (1.54)	14.99 (1.33)
Tertiary							
45-85	222	95.55 (4.52)	17.86 (0.64)	24.32 (2.15)	12.42 (1.63)	25.36 (1.19)	15.57 (0.91)
95% CI		94.96-96.15	17.78-17.95	24.03-24.60	12.21-12.63	25.21-25.52	15.45-15.69
<55	101	95.73 (3.47)	17.92 (0.35)	24.06 (2.03)	12.74 (1.38)	25.48 (0.71)	15.50 (1.07)
55-64	68	96.54 (2.66)	17.90 (0.29)	24.90 (1.51)	12.45 (1.51)	25.59 (0.68)	15.68 (0.67)
65-74	41	93.34 (7.87)	17.60 (1.34)	23.92 (3.13)	11.67 (2.20)	24.63 (2.23)	15.50 (0.86)
75+	12	95.88 (3.16)	17.90 (0.30)	24.55 (1.64)	12.05 (1.21)	25.55 (0.67)	15.72 (0.71)

Table 14: Weighted Means, (Standard Deviations) for 'Kiwi' ACE-R Score by Highest Qualification attained and by Age Group

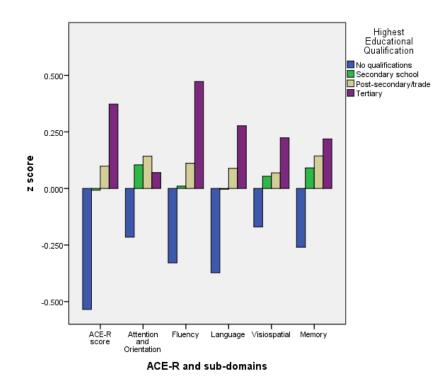


Figure 4: Estimated Marginal Means for the 'Kiwi' ACE-R by Age and Educational Qualification

*Ethnicity.* Analysis of variance showed a significant main effect for ethnicity, F (4, 952) = 3.33, p<.00,  $\eta^2$ =0.01 (small effect). When age, education and sex were controlled for this main effect increased in significance, [F (7, 932) = 31.67, p<.00,  $\eta^2$ = 0.19]. Post-hoc Bonferroni analyses showed that New Zealand Europeans (M = 93.84 SD = 4.7) scored significantly higher than Māori (M=92.07, SD=6.29, mean difference = 1.77) and Pacific Peoples (M=87.6, SD=18.64, mean difference = 6.22). There were no significant differences between Māori and New Zealand European scores on the 'Kiwi' ACE-R domain scores. This is illustrated in Figure 5. Table 15 shows the 'Kiwi' ACE-R mean scores (standard deviations) and 95% confidence intervals broken down by two ethnic groups (New Zealand European and Māori) and across the four different age groups. Sample sizes for other ethnic groups were too small to warrant subsample analysis (e.g., by age).

Age Group	Ν	'Kiwi'	Attention/	Memory	Verbal	Language	Visual-spatial
•		ACE-R	orientation	·	Fluency		-
New					•		
Zealand							
European							
45-85	862	93.84 (4.73)	17.86 (0.47)	24.01 (2.25)	11.55 (2.03)	24.99 (1.48)	15.41 (0.95)
95% CI		93.53-94.1	17.84-17.89	23.86-24.16	11.41-11.68	24.89-25.09	15.35-15.47
<55	247	95.45 (3.47)	17.93 (0.29)	24.32 (1.93)	12.14 (1.73)	25.38 (1.10)	15.62 (0.71)
55-64	315	94.6 (3.93)	17.87 (0.37)	24.38 (1.93)	11.69 (1.91)	25.12 (1.39)	15.52 (0.82)
65-74	202	92.5 (5.39)	17.78 (0.76)	23.67 (2.61)	11.13 (2.27)	24.82 (1.43)	15.21 (1.13)
75+	98	90.01 (5.55)	17.88 (0.32)	22.79 (2.66)	10.46 (2.05)	24.08 (1.94)	14.96 (1.20)
Māori							
45-85	76	92.07 (6.29)	17.77 (0.65)	23.22 (3.25)	11.50 (2.32)	24.52 (2.07)	15.48 (0.85)
95% CI		90.63-93.50	17.62-17.92	22.48-23.96	10.53-11.58	24.05-24.99	15.29-15.68
<55	32	92.93 (6.4)	17.70 (0.69)	23.89 (2.22)	11.27 (2.48)	24.40 (2.44)	15.62 (0.57)
55-64	30	92.08 (6.48)	17.87 (0.46)	23.03 (4.02)	10.99 (2.13)	24.61 (1.82)	15.35 (1.00)
65-74	10	91.25 (4.78)	17.81 (0.75)	22.38 (3.00)	10.56 (2.31)	24.83 (1.52)	15.55 (0.88)
75+	4	89.29 (9.91)	17.50 (1.27)	21.49 (4.37)	11.05 (3.03)	24.04 (2.29)	15.19 (1.46)

Table 15: Weighted 'Kiwi' ACE-R and Sub-Domain Means, (Standard Deviations) and 95% Confidence Intervals for New Zealand European and Māori by Age Group

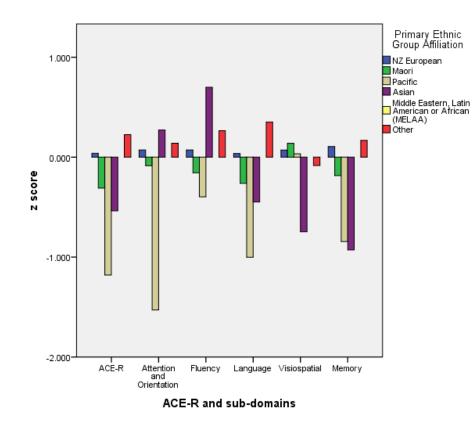


Figure 5: Standardized Mean Scores of 'Kiwi' ACE-R Domains by Primary Ethnic Affiliation.

*Gender.* When examining the sample as a whole, there was a significant gender difference. A two-tailed t-test of independent means showed that females scored significantly higher on the ACE-R (M= 94.58, SD= 4.65), than males (M= 92.70, SD= 5.36), t (944) = -5.91, p<.00, d= -0.37 (medium effect). Levene's test indicated unequal variances (F= 13.82, p=0.00), so degrees of freedom were adjusted. This effect remained significant and increased when age, education and ethnicity were controlled for [F (4, 932) = 46.40, p<.00,  $\eta^2$ = 0.16]. Women performed significantly better in the domains of fluency, language and memory and also were better able at free recall and delayed recall of word lists. Literature indicates that women tend to perform better than males on learning and recall trials, and use semantic clustering strategies to aid retrieval more than males (Kramer, Delis, & Daniel, 2006). Table 16 shows the 'Kiwi' ACE-R means (standard deviations) and 95% confidence intervals for males and females for the sample as a whole and across the four age groups and Figure 6 illustrates this, collapsed by age.

Age Group	N	'Kiwi' ACE-R	Attention/ Orientation	Memory	Verbal Fluency	Language	Visual-spatial
Male							
45-85	475	92,69 (5,35)	17.86 (0.42)	23 41 (2.67)	11 21 (2.15)	24 78 (1 67)	15.41 (0.97)
95% CI	175	92.21-93.17	17.83-17.90	· · ·	11.01-11.40	24.63-24.93	· /
>55	134	93.49 (4.87)	17.88 (0.41)	23.52 (2.50)	11.74 (1.82)	24.79 (1.69)	15.54 (0.96)
55-64	177	93.67 (4.88)	17.88 (0.33)	23.93 (2.47)	11.33 (2.06)	24.95 (1.69)	15.56 (0.78)
65-74	117	92.24 (5.30)	17.81 (0.53)	23.35 (2.78)	10.92 (2.43)	24.90 (1.32)	15.24 (1.09)
75+	47	87.87 (5.92)	17.89 (0.41)	21.28 (2.63)	9.90 (1.96)	23.85 (2.03)	14.94 (1.16)
Female							
45-85	524	94.58 (4.64)	17.85 (0.58)	24.34 (2.15)	11.86 (1.93)	25.14 (1.38)	15.37 (0.97)
95% CI		94.18-94.97	17.80-17.90	· · ·	, ,	. ,	15.29-15.46
>55	164	96.24 (2.95)	17.93 (0.30)	24.67 (1.61)	12.39 (1.74)	25.63 (0.77)	15.61 (0.71)
55-64	191	95.12 (3.49)	17.87 (0.40)	24.57 (1.92)	12.02 (1.70)	25.22 (1.14)	15.42 (0.88)
65-74	111	92.57 (6.65)	17.71 (1.04)	23.76 (2.83)	11.28 (2.17)	24.69 (1.82)	15.12 (1.18)
75+	58	91.95 (4.78)	17.82 (0.43)	23.81 (2.44)	10.92 (2.04)	24.34 (1.84)	15.04 (1.23)

Table 16: Weighted Means (Standard Deviations) and 95% Confidence Interval for 'Kiwi' ACE-R Scores Across Sex and Age Group.

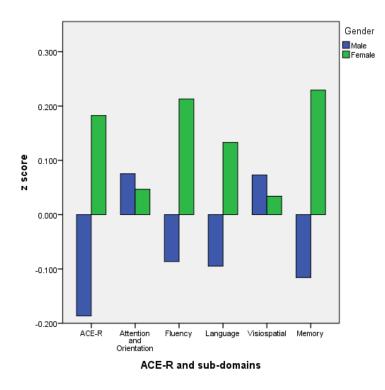


Figure 6: Estimated Marginal 'Kiwi' ACE-R Means for Males and Females by Age Group

# Explaining the variance

Age, education, ethnicity (Māori and New Zealand European) and sex individually explained 9-19% of the variance in 'Kiwi' ACE-R score. When these variables were entered as predictors into a linear regression model, controlling for the covariance effects, together they explained 19.8% of the variance [F (4, 919) = 57.66, p<.00]. This suggests that there is a large interaction between the variables, [F (4, 870) = 2.53, p<.04].

# Comparison of cognitive score with HRS data.

Outcome scores from measures used in the United States longitudinal study (HRS) were compared to the scores on the scales in the current sample, and are summarised in Table 17. These were compared in order to see if the New Zealand cognitive ageing profiles match the United States sample. This will help to inform public policy and practice from an international perspective. Participants in the NZLSA study scored significantly higher on Immediate Recall, Delayed Recall, Total Recall, Serial 7's and Vocabulary. It is unclear whether age or education differences between the two samples would have had an impact on the significant differences.

	HRS 2008 (51+ years)	NZLSA 2010	T-test of significance
		(45-85 years)	
Immediate Recall (10 points)	5.36 (1.71), n=16077	6.64 (1.66)	t(17080) = 23.06,p<0.00
Delayed Recall (10 points)	4.32 (2.05), n=16077	4.52 (2.26)	t(17080) = 3.06, p < 0.00
Total Recall (20 points)	9.68 (3.76), n=16077	11.16 (3.65)	t(17080) = 12.13, p < 0.00
Serial 7's subtraction (5 points)	3.48 (1.70), n=16077	4.93 (0.38)	t(15701) = 23.32, p < 0.00
Vocabulary (2006) (10 points)	5.45 (2.07), n=10517	7.84 (1.60)	t(11520) = 35.60, p < 0.00

Table 17: Means (SD) and T-Test Comparisons between HRS (2008) and NZLSA (2010) Results

Note. HRS data from: (Fisher, Hassan, Rodgers, & Weir, 2012).

# Outliers.

Exploratory data analyses were conducted to identify outliers in the distributions of scores for the 'Kiwi' ACE-R. Statistical analysis of the sample was suggestive that participants who scored equal to, or less than 84 (N=50), were considered outliers (at or below the 5<sup>th</sup> percentile), suggesting an inability to understand instructions, difficulty with performance due to sensory or motor disorder, or cognitive decline due to degenerative neurological disorder. It is possible that the sample contained cases of undiagnosed mild cognitive impairment or early stage degenerative dementia. Compared to the sample that scored >84, the 5<sup>th</sup> percentile group were more likely to have no qualifications (40.2% vs. 16.2%), be male (63.7% vs. 46.5%) and older 75+, (29.4% vs. 9.5%). Māori participants made up 16.5% of the 5<sup>th</sup> percentile group compared to only 7.1% of the higher scoring group. Outliers were maintained in this data set as it is a normative sample, and as such, top and bottom scorers are included.

## Cognitive Impairment.

Based on the suggested ACE-R cut-off scores for cognitive impairment in the original development paper, 82: sensitivity = 0.84, specificity = 1.0), 33 people (3.29%) would be classified as cognitively impaired. Impairment generally increased across age groups. Percentage of participants that scored below the cut-off for each age group are: <55 (3.35%), 56-64 (1.35%), 65-74 (4.78%), 75+ (6.66%).

## Discussion

The aim of this study was to assess cognitive functioning in older community dwelling New Zealanders and provide demographically stratified national norms for the 'Kiwi' ACE-R.

As expected, the 'Kiwi' ACE-R score was highly correlated with the MMSE and other measures of cognitive ability (comprehension, abstract reasoning and free/delayed memory recall). This suggests that the ACE-R shows good concurrent validity. The alpha coefficient for the 'Kiwi' ACE-R was acceptable based on the recommendation of alpha 0.70 (Chronbach, 1951). Other research using the ACE and the ACE-R report alpha levels ranging from 0.80-0.92 (Garcia-Caballero et al., 2006; Konstantinopoulou et al., 2010; Larner, 2007; Mathuranath et al., 2007; Mioshi et al., 2006a) or are unknown, (Alexopoulos et al., 2007; Chade et al., 2008; Jones, Franczak, & Antuono, 2008; Law et al., 2012; Tarek & Gaber, 2008). It is possible that the current study had a lower alpha level compared to other research because the 'Kiwi' ACE-R was being used with a non-clinical sample, and therefore the items in the test created less variance and there was more chance of ceiling effects.

On a number of items all participants scored the maximum points available, (e.g., fragmented letters) or very high in domains, (e.g., 98% scored top points in the attention/orientation domain). This suggests that some items show ceiling effects and are not as good at differentiating between cognitively intact participants and cognitively impaired participants. This will likely impact evidence of cognitive improvement in future testing. For example, if participants score the highest possible points, any improvements that may occur in their cognitive functioning ability will not show within these items or sub-domains.

Results suggest that scores on the 'Kiwi' ACE-R do not significantly differ from the original normed control group (Mioshi et al., 2006a). The original group were highly educated, (like the present sample) and had a similar mean age. Matching on these two domains likely increased the chances that scores would be similar. These scores suggest that this New Zealand community

sample show similar cognitive functioning levels as the United Kingdom group and that the changes made to the 'Kiwi' ACE-R to make it more culturally acceptable did not affect the integrity of the assessment.

The finding that age impacts on 'Kiwi' ACE-R scores reflects previous research that shows cognitive ability declines with age (Albert et al., 1993; Christensen et al., 1999; Cullum et al., 2000; Salthouse, 2002) and supports the use of 'Kiwi' ACE-R score age stratified norms (Mioshi et al., 2006a). In the future it may be useful, (if sample size permits) to categorise the older age groups into smaller age ranges due to the increased heterogeneity in older age group samples on cognitive testing (Mungas et al., 2010).

The education effect on 'Kiwi' ACE-R score was significant in this study, showing that people with higher qualifications perform better on the 'Kiwi' ACE-R. Other studies have reported mixed results on the impact of education. In the original normed sample education had little effect on scores; however, the control sample was matched in age to the clinical samples which effectively controlled for educational level (Mioshi et al., 2006a). In a Spanish validation study education was dichotomised into less than or greater than 14 years. Significantly different mean original ACE scores were found for the two groups and this prompted the development of different cut-off scores for impairment (Garcia-Caballero et al., 2006). Furthermore, a Malayan validation study found education level was the only demographic parameter that affected the original ACE and thus education-stratified cut-off scores were developed (Mathuranath et al., 2000). More recently, a study found that performance of healthy middle-aged and elderly individuals on the ACE-R was strongly influenced by education and, to a lesser extent, by age (Amaral-Carvalho & Caramelli, 2012). It is possible that the high level of education in the present sample enhanced participants' performances through greater familiarity and comfort with formal assessment, improved maintenance of cognitive skills (Cullum et al., 2000), delay of clinical symptoms (Tuokko et al., 2003) or provided a surrogate for environmental influences (Powell & Whitlia, 1994). The results in this study highlight the importance of using the qualification level

stratified norms, particularly due to the large heterogeneity in education levels that is seen within the New Zealand population.

In this study ethnicity had an impact on 'Kiwi' ACE-R scores. Due to small numbers for a number of different ethnic groups, outliers tended to impact the mean scores quite significantly and thus only New Zealand European and Māori ethnicities were presented in norm groups.

It has been suggested that education and age may have been significant factors in accounting for cultural differences that have been found (Barker-Collo et al., 2002). For example, Barnfield and Leathem (1998) found that Maori performed lower on items that required formal Western education and concepts (e.g., verbal memory). As noted by, Rosselli & Ardila (2003) the effects of culture on neuropsychological assessment may be ameliorated by successful education within the educational system of the dominant culture. Analysis showed that differences on 'Kiwi' ACE-R scores between the two ethnicities were only significant in the no qualification group; New Zealand European (M=91.48, SD=5.78) scored significantly higher than Maori (87.71, SD=7.17) with a mean difference of 3.77 points. When age and education were controlled for in this study, significant differences in 'Kiwi' ACE-R score persist, suggesting that differences between Māori and New Zealand European 'Kiwi' ACE-R scores were present irrespective of education level (despite the difference only being significant in the no qualifications group) and age. Māori were over-represented in the no qualification category. Significant differences between Maori and New Zealand European groups with no qualifications were found in sub-domains of Language (comprehending instructions, repetition of a sentence, naming and language comprehension), Memory (3 item recall, anterograde and recall/recognition) and Fluency (animals).

Another study looking at ethnic differences in cognitive tests found that healthy Māori students with no qualifications (aged 16-30) perform significantly below similarly matched New Zealand Europeans in tasks of vocabulary, speed of comprehension, cognitive switching and immediate/delayed recall of contextual information (Ogden, Cooper, & Dudley, 2003). When

looking at similar cognitive tasks in this study (vocabulary and immediate/delayed word lists), Māori performed significantly lower on these tasks as well (when education and age were controlled for).

There is very little research into why ethnic differences in performance on cognitive tasks occurs. It has been suggested that tasks involving Western concepts may be more difficult for Māori participants to score highly on (Barker-Collo, 2001; Barnfield & Leathem, 1998). While other researchers suggest that bilingual speakers produce greater variability in responses (Kohnert et al., 1998), potentially due to a difficulty in supressing activation of their first language (Hermans et al., 1998). In further assessments it may be beneficial to ascertain the primary language spoken of participants, but it is unlikely that in this sample Te Reo, (Māori language) was a common first language.

Despite the knowledge of cultural bias, most researchers acknowledge that test content and administration procedures are invariably culturally bound (Haitana, Pitama, & Rucklidge, 2010). Test developers acknowledge the need to consider the impact of test content, test materials and test conditions on the reliability and validity of a test in an attempt to minimise the effects of cultural bias. Ogden and McFarlane-Nathan (1997a) and Shepherd and Leathem (1999) noted that Māori individuals may find clinical assessment environments particularly uncomfortable and thus perform at lower levels. Ultimately, these results illustrate the importance of using appropriate norms for different ethnic groups and ensuring participants feel as comfortable as possible in the testing environment (e.g., assessment in their own home).

Explanatory value can be given to the structural inequalities that exist between ethnicities within New Zealand. Given the multiple risk factors for poorer cognitive functioning, such as physical activity, lower education, (often a surrogate for environmental experiences that can impact on cognition, e.g., illness, health, socio-economic status and better access to medical care) and physical health (e.g., cardiovascular attacks increases risk of cognitive decline) it is plausible that ethnic disparities at a structural level can explain the differences shown in cognitive functioning performance.

Research shows a progressive widening gap in survival chances between ethnic groups over the past twenty years, (with those from New Zealand European ethnicity showing higher survival than people from Māori ethnicity); a result of widening differentials in chronic disease mortality in middle and older age, (Ajwani, Blakely, Robson, Tobias, & Bonne, 2003). Ajwani et al., (2003) explain this through three main categories: epidemiological (i.e., risk factors and diseases such as cardiovascular disease and diabetes), social structural (i.e., policies and reforms), and health services (i.e., access and quality). It is argued that the epidemiological risk factors experienced more by Māori are seen as distal social determinants of health. For example, smoking is strongly associated with increased deprivation (Salmond & Crampton 2000), and negatively associated with increasing income (Thomson, O'Dea, Wilson, Reid, & Howden-Chapman, 2000). Furthermore, gaps between ethnicities in key social determinants of health such as employment status, education, income and housing increased during the social and macroeconomic reform changes in the early 1990's (Tobias & Howden-Chapman, 2000) and the 1990s saw a significant drop in resources going to Maori communities following the 'mainstreaming' of Maori services (Cunningham & Durie, 1999). Compounding these problems is a noted discrimination against Māori in the job market (leading to poorer occupational status and wages) (Sutherland & Alexander, 2002) and systematic discrimination against Māori in the welfare system (Hackwell & Howell, 2002). In addition, there is also differential access to, and quality of receiving, health care services, with Māori and Pacific People receiving fewer cardiac interventions than would be expected (Tukuitonga & Bindman, 2002), even when controlling for gender, age and deprivation (Westbrooke, Baxter, & Hogan, 2001). There is New Zealand evidence for: ethnic differences in access to, and quality of, health care, structural change in New Zealand society during the last 20 years and epidemiological risk factors that have adversely impacted on Māori. It is highly plausible that the widening social inequalities between ethnic groups have in turn led to widening health inequalities; with performance in cognitive functioning tests being one potential consequence of these inequalities.

Due to the lack of a standardized definition of cognitive impairment (Busse, Bischkopf, Riedel-Heller, & Angermeyer, 2003; Petersen et al., 1999; Winblad et al., 2004), rates of impairment are difficult to estimate in the community. Rates differ depending on what cut-off score on a certain test is assumed to be the most accurate in differentiating between intact cognitive functioning and impaired cognitive functioning. The utility of the standard 'Kiwi' ACE-R has been investigated using a clinical group of older people from Wellington (aged 75 years +) and the ideal cut-off score on the ACE-R for identifying dementia was 76.5; the best balance between sensitivity (84.5%) and specificity (79.6%), (Strauss et al., 2012). This is similar to the cut-off score suggested by Kwak and colleagues, (Kwak et al., 2010). However, it is quite different to the cutoff obtained with the original population on which the ACE-R was developed (a score of < 88maximising sensitivity and <82 maximising specificity), suggesting that New Zealand clinical samples require a lower cut-off for diagnosing dementia. This supports the research showing that New Zealand participants tend to score lower than the standardized norms on many cognitive tests, (Barker-Collo, 2001; Barker-Collo et al., 2002; Sothieson, 2010). Using the cut-off recommended by Strauss et al., (2012), 1.1% of this current community based nationwide sample would likely have dementia, whereas using the Mioshi (2006a) cut-off 3.29% of this sample would likely have dementia. Using a more widely accepted cut-off for suspected dementia (>2 standard deviations) below a standardized norm mean, ACE-R score of <83.2), then 4.2% of this sample may show signs of cognitive impairment (and possibly dementia). This latter prevalence rate is similar to other community samples such as the HRS study which estimated an impairment rate of 6% of those aged 70+ living in the community (Suthers et al., 2003). It is possible that the lower rate in this New Zealand sample is an illustration of sampling from a variety of age groups as opposed to just over 70 year olds. The large variability in options for cut-off scores suggests that more research is needed to identify and validate an appropriate cut-off scores.

This study included all outliers in analyses and presentation of data, (50 people scoring below 84 points on the 'Kiwi' ACE-R). Outliers were included as they are representative of the community the sample was drawn from and reflect variation in the population. There has been previous debate about including or excluding outliers (Osborne & Overbay, 2004). If data points which are outliers are deemed to be legitimate, data is more likely to be representative of the population as a whole (Orr, Sackett, & DuBois, 1991). However, research has shown that removing extreme scores helps to increase the accuracy significantly and errors of inference can drop significantly. It is possible that by presenting the norms as scaled scores it may increase the accuracy of the norms through minimising the effect of outliers on the mean scores. Scaled scores would take into account the outliers, however they would only affect the outer extreme scores.

# Limitations

There are a number of limitations to this study which may impact on the interpretation of findings. One of the most well researched cognitive domains and one that is affected first by the consequences of ageing is processing speed (Salthouse, 1996). Unfortunately the ACE-R does not include this as a domain. This cognitive domain would need to be clinically judged based on the performance of the person and used as qualitative information or tested independently of the ACE-R.

A further limitation is the lack of participants from minority ethnicities such as Pacific Peoples and Asian groups. New Zealand is a multicultural and ageing society and as such cognitive screening tests will need to be developed appropriately to meet the anticipated demand for accurate assessment across different ethnic groups. There is a need to have studies that oversample these groups in the future.

The present study did not specifically assess subjective cognitive difficulties or whether participants had any existing diagnoses of cognitive impairment. This limits the research into participant's insight into difficulties, as well as the ability to control for cognitive impairment (subjective and objective) in this sample. In analysis of 'other health problem' no participant endorsed cognitive problems.

#### Future Directions

In 2012 it became illegal to use the ACE-R due to the recently copyrighted MMSE being embedded within it. It may be possible to purchase a license for the MMSE which will allow for the ACE-R to continue to be used in this (NZLSA) and other longitudinal studies. Currently the ACE-III is being validated (a version with no MMSE items in it) and has shown equivalence with the ACE-R (Hsieh et al., 2013) and there is a workgroup developing 'Kiwi' ACE-III. Once this is released a validation study could be instigated to examine any significant changes to 'Kiwi' ACE-R scores.

The basic purpose of cognitive screening tests is to indicate the likelihood of genuine cognitive impairment, inferred from the relationship of the patient's score to reference norms (Cullen et al., 2007). This normative data can be used to track changes in cognitive ability at both an individual level, (with repeat testing) and by following population trends.

## Conclusion

The data presented in this study provides a basis for interpreting scores from older people assessed with the 'Kiwi' ACE-R. This study confirmed the usefulness and acceptability of this measure in New Zealand and also highlighted the need for specific Māori and New Zealand European norms. The representative, population based sample of older New Zealanders allows for the monitoring of cognition in older adults and provides appropriate reference for comparison. Furthermore, the inclusion of ethnically stratified scores is the first known attempt at providing an appropriate comparison point for Māori New Zealanders. This research has highlighted the need for different norms for cognitive assessment tools amongst ethnicities, education levels, gender and age groups in New Zealand.

Competing interests: None

# CHAPTER FIVE: QUALITY OF LIFE AND COGNITIVE FUNCTIONING IN OLDER AGE

#### Background

Early notions of quality of life can be dated back to Aristotle's (384-322 B.C.) written concepts of 'the good life' and 'living well', which explored both individual and societal concepts of quality of life. In 1889 quality of life was conceptualized as a "morality to which to aspire; a regard of not just quantity but also the quality of life" (James Seth, The Evolution of Morality, p.43). The concept gained more attention in the 1950s and 1960s in relation to economics, and since then, other indicators of well-being (besides income) were thought to be important for a good quality of life, such as education, housing, and access to healthcare. The term has been used in a number of disciplines ranging from: philosophy, politics, geography, psychology, marketing and the medical sciences (Bowling, Banister, Sutton, Evans, & Windsor, 2002).

This chapter explores the complexity of the conceptualization, definition and measurement of quality of life, with focus on research with older adult populations. The proposed function of cognitive functioning within the concept of quality of life is explored and studies investigating this relationship are reviewed.

#### Definition and Conceptualization of quality of life in older adults

Despite the multitude of research on quality of life, the concept has consistently evaded consensus, largely due to the various ways that the term has been used (Albrecht & Devlieger, 1999). Models of quality of life range from the basic objective and subjective needs-based approaches, to classic models based on psychological wellbeing, morale and life satisfaction, physical health and functioning, social expectations and perceptions and the importance of social and personal resources (Baltes & Baltes, 1990; Baltes & Smith, 2003). The lack of theoretical grounding has created little consensus around the meaning of the term and there is a trend toward divergence, with no generic definition that satisfies everyone. The only apparent agreement is that

it is a multi-dimensional construct, although the number and kind of dimensions remain controversial, (Smith, Sim, Scharf, & Phillipson, 2004).

One of the most influential conceptualizations of quality of life is that of Lawton who described it as "the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of an individual in time past, current and anticipated", (Lawton & Powell, 1991, p. 6). Lawton's conceptual framework is intended as a meta-construct, and presumes to account for all areas of life; for every aspect of behaviour, environment and experience. Lawton arranged the dimensions on a continuum of objective (environment and behavioural competence) and subjective (perceived quality of life and subjective well-being) and argued that both were important for quality of life. His conceptualization of domains forms a hierarchy so that objective dimensions are antecedent to subjective ones. A criticism that arose from this conceptualization is that Lawton mixed antecedents and consequences (Netuveli & Blane, 2008). However, there are very few quality of life measures that separate antecedents (predictors) and consequences (outcomes) and it is an ongoing challenge in research (Hyde, Wiggins, Higgs, & Blane, 2003a) (Moons, Budts, & De Geest, 2006).

Lawton (1997, p. 91) noted that "quality of life is defined in so many ways by so many people and, regrettably, often is not defined." The World Health Organization (WHO) have created a definition of quality of life which is commonly used, but not explicitly for older people. The WHO have defined quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It covers physical wellbeing, (self-sufficiency, illness symptoms, mobility), psychological wellbeing, (emotions, behaviour, cognitive status) and social wellbeing, (one's role in relation to others), (The WHOQOL Group, 1994). The definition of quality of life as a multi-dimensional construct has led to the development of models that aggregate measures of different aspects of function (The WHOQOL Group, 1994) so that quality of life is not simply equated with the terms health status, life style, life satisfaction, mental state, or well-being. Rather, it is a concept that incorporates the individual's perception of these and other aspects of life, while at the same time taking into account the wider social circumstances. This is consistent with Lawton's conceptualization but does not take into account objective facets of quality of life, thought to be antecedent to the subjective perception.

There are a variety of components indicated as key to quality of life and these differ across the life-course. These include: social factors, (e.g., social capital and cohesion), psychological variables, (e.g., adaptation, self-mastery, self-efficacy, morale, self-esteem) and perceived control over life, social comparisons, expectations of life, optimism-pessimism, social values, beliefs and aspirations (Baltes & Baltes, 1990; Lawton & Powell, 1991; Netuveli, Wiggins, Hildon, Montgomery, & Blane, 2006b). Other known factors include (but are not limited to); autonomy, future past and present activities, social participation (Padoani et al., 1998), anxiety (Smith, Avis, & Assmann, 1999), depression (Logsdon, Gibbons, McCurry, & Teri, 2002b; Slawek et al., 2005), severity of cognitive impairment and other neuropsychiatric symptoms (Ready, Ott, & Grace, 2004; Selai, 2001). Health is a large predictor of quality of life and is one of the most widely used outcome measures in quality of life research (Avis et al., 1996; Niemi, Laaksonen, Kotila, & Waltimo, 1988; Ritsner, 2007; Smith, Avis, Mayer, & Swislow, 1997). These variables all appear to play a complex and overlapping role in predicting quality of life ratings.

#### **Measuring Quality of life**

The historic divergence of meaning and the inherent multi-dimensionality of the concept is mirrored by the absence of agreement on its measurement (Smith, 2000); a decade ago it was determined that there were over 1000 measures of quality of life (Thorgrimsen et al., 2003). Many measures are inadequate single domain scales assessing needs such as psychological (subjective well-being, happiness and life satisfaction), morale, activity level, physical health (general and disease-specific), social (relationships and networks) and functional status (Cella, 1994; Gabriel & Bowling, 2004). Other scales that aggregate measures of various aspects of functioning, and

approximate a single index, do not provide information about the relative importance of each of the major dimensions of the aspects of quality of life (Cella, 1994).

There is contentious debate about whether quality of life constitutes objective dimensions, subjective dimensions or both (Testa & Simonson, 1996b). Objective dimensions refer to the observable life conditions or physical functioning that can be operationalized by tests. Subjective dimensions refer to the respondent's perceptions (Moons et al., 2006). Subjective evaluation of quality of life has gained importance, highlighting that it is not only the conditions of life but also, and more importantly, the experience of those life conditions which is important to quality of life (The WHOQOL Group, 1994). A subjective approach to measuring quality of life relies on a person's self-appraisal based on implicit criteria and is influenced in a complex way by the person's physical health, psychological state, level of independence and social relationships (Netuveli & Blane, 2008).

Self-report, subjective scales respect the autonomy of the person (Ritsner, 2007) and have been reported to be more powerful than objective economic or socio-demographic indicators in explaining the variance in quality of life ratings (Bowling et al., 2002; Bowling & Stenner, 2010). This is largely because objective indicators of quality of life could be perceived differently by different people (Ettema et al., 2005) and an individual's perceptions of which facets of life are important can vary considerably (Higginson & Carr, 2001). This conclusion is supported by findings from the literature on the disability paradox (Albrecht & Devlieger, 1999), which finds that disabled people unexpectedly experience a good quality of life, even though most external observers may assume that that life would be undesirable. The disability paradox, addresses the disparity between objective conditions and subjective experiences and it is the subjective appraisal that has the largest influence. Consequently, individuals are the only ones who can *reliably* estimate their own quality of life. While it is noted that subjective evaluation is essential, it also gives rise to confusion in that only the individual is able to determine what really

constitutes quality and yet, it is often the researcher who determines what aspects are measured (except in narrative reviews).

Lawton (1991) argues for a conceptualization that incorporates both subjective and objective dimensions. A more objective conceptualization of quality of life measures the degree to which life meets explicit standards of the 'good life' external to the individual as assessed by an impartial outsider, (e.g., educational achievement, income, occupational status, health, family, standard of living, and longevity) (Lawton, Winter, Kleban, & Ruckdeschel, 1999a). The use of objective measures are useful at a population level as they facilitate comparability by treating all individuals in the same way, (because ratings are based on pre-defined criteria like affect and physical health) and can control for variations in people's expectations and experiences (King, 2007). However, there can be uncertainty about what is being observed with objective ratings because they can be based on an implicit set of normative assumptions about each person's quality of life and often neglect the range of experiences of people in older age and neglect the cognitive processes that mediate a person's perception of quality of life; that is, how someone feels is only partially related to their observable behaviour and is also influenced by current expectations around their functional level as well as perceptions about their environment (Cella, 1994). Limitations of this approach include uncertainty about whether what is being observed is what the individual deems to be important to their quality of life and it may also be subject to similar biases as proxy ratings.

Due to the inherent difficulties in objective ratings, within a concept that is largely subjective, objective and subjective ratings of quality of life can vary substantially and often there is little agreement between the two (Selai, 2001; Teng, Tassniyom, & Lu, 2012). This can cause difficulties in making conclusions about what is important for quality of life at population or individual levels. Measures that combine both objective and subjective information and the relative importance placed on each of these components of quality of life may be favourable to either alone.

## Quality of life in Older Age

Aristotle suggests that each person or even the same person values different things at certain times in their life depending on their situation; and thus factors of value in quality of life are likely to change. For example, one's quality of life evolves through the continual change in values and priorities in response to life stages and circumstances (Moons et al., 2006). The dynamic nature of the concept requires a life-course approach to its conceptualization, definition and measurement; a reflection of the fluidity (Higginson & Carr, 2001). Despite this, quality of life in older age remains a neglected area of research (Gabriel & Bowling 2004, Lawton 1999).

There is increasing interest in the enhancement and measurement of quality of life in older age. Interest in the quality of life of older people originates from a number of factors. Firstly, the demographic shift that has resulted in unprecedented proportions of older adults (especially among the populations of the developed world) which presents unique challenges in terms of meeting health and social care needs (Netuveli & Blane, 2008). Secondly, advances in medical technology have added years to life, but not necessarily quality of life. Thirdly, there has been a shift in focus away from secondary and tertiary implementation, to primary intervention and prevention (Keeling, 1999; Ministry of Social Development, 2001). Current policy is concerned with enabling older people to maintain their independence, actively contribute to society and respond effectively to the challenges that come with older age; that is adding quality of life to years of life (Bowling et al., 2002; Ministry of Social Development, 2001). Finally, the nature of ageing itself is changing. The older person has become more active and flourishing in this new stage of life after exiting the work force, (Cella, 1994).

Quality of life can be quite difficult to assess in older people because the usual factors that are predictors of quality of life are factors that are part of the normal ageing process. For example, in older age physical abilities tend to decline bringing about dependence on others and important events such as retirement, reduced income and less social interaction may increase feelings of being lonely and isolated and therefore reduce the standard of living (Padoani et al., 1998). Thus it is important when assessing quality of life to keep in mind the life stage that someone is at and the impact this may have on their ratings.

Studies assessing what is deemed important to quality of life in older age find that the priorities placed on different factors of quality of life change with age. A multiple regression analysis of a large population based sample (n=6,711 aged 65 years + in Britain), suggested that the main independent predictors of global quality of life in older age were: social comparisons and expectations, personality and psychological characteristics, health and functional status and social capital (Bowling et al., 2002). These variables together explained 26.7% of the variance in quality of life ratings. The most statistically significant factors in the model were social comparisons and expectations, optimism-pessimism, functional ability, number of social activities, social support, feelings of loneliness, rating of the quality of the area (e.g. available facilities and feeling safe), health values, and respondents' sex.

These results are replicated in other large surveys (Farquhar, 1995; Gabriel & Bowling, 2004) and were common areas in younger people's quality of life as well but the priorities change (Gabriel & Bowling, 2004). Other factors that have emerged are having nice and enjoyable neighbourhood, comfortable houses and good public services, psychological factors (e.g., optimism, contentment, looking forward to things, acceptance and other coping strategies), financial security and not having to depend on others (Bowling, Gabriel, & Dykes, 2003). A validation study of the WHOQOL-BREF (a quality of life measure of 4 different domains of quality of life) across 23 countries and spanning ages 12-97 (n=11, 380) found that mean domain scores decreased with age group with the greatest changes found in physical health (Skevington, Lotfy, & O'Connell, 2004); suggesting that physical problems may be a more significant impact on an older person's quality of life ratings than younger person. However in another study (n=1000) with similar age groups, focusing on well-being which did not assess health specifically, (life satisfaction, quality of life, happiness), all measures of subjective well-being showed an increase with age particularly

after 40 years of age and then a drop for those over 75, but still above the ratings of those under 40 (Horley & Lavery, 1995). Quality of life is measured differently in these samples and it shows that depending on what aspects of quality of life are measured, results can vary substantially.

In a New Zealand narrative study of quality of life ratings (both positive and negative) of older people who were receiving low-level home support, (Hambleton, Keeling, & McKenzie, 2008), themes that emerged as important for maintaining positive quality of life in older age included: having good people around (family, friends, neighbours), looking after oneself and keeping meaningfully active within the community, managing ill health, living with personal and physiological losses, age related expectations and looking to the future, (particularly personal health and what supports may be needed). These views were closely interlinked, similar to other research showing the interconnectedness of quality of life dimensions (Gabriel & Bowling, 2004; Hendry & McVittie, 2004; Higgs et al., 2003) and akin to identified dimensions found in other studies on quality of life in old age (Farquhar, 1995; Bowling & Windsor, 2001; Gabriel & Bowling, 2004; Raphael, 1996). In the New Zealandstudy ill health and loss were noted as detracting from quality of life. However, it was concluded that the negative impact of either present or anticipated ill-health was mitigated by the other positive quality of life experiences in their lives.

## Cognition and quality of life

In both Lawton's (1991) conceptualization and the World Health organization's (The WHOQOL Group, 1994) definition of quality of life, cognitive functioning is mentioned as having a role in both behavioural and psychological aspects of quality of life. Despite cognitive functioning being an important aspect to quality of life it is rarely studied in conjunction with the concept.

Special attention needs to be paid to the cognitive functions, which can be considered important factors that influence subjective assessment of quality of life (Padoani et al., 1998). If self-reports are to be useful, they require the individual to have the ability to participate in the assessment. For

example, having poor cognitive functioning may impact on the ability to accurately assess subjective quality of life and lead to inaccurate assessments due to misunderstanding, misinterpreting or miscommunicating of subjective information (Logsdon et al., 2002b). Inaccurate evaluations by people who are intellectually unable to assess life situations (e.g., intellectual disability, traumatic brain injury or dementia) is known as a cognitive fallacy (Katschnig, 1997).

Similar to the affective fallacy (where current affective states can distort perception), the cognitive fallacy can impact on the recall of information which is subject to modification by previously stored information and by other new and existing inputs (Gabriel & Bowling, 2004). While subjective self-reports are the most accurate in terms of individual perspectives, there is a chance that cognitive impairments may influence the ability for people to accurately complete an assessment andinfluence the validity of self-reports. A particular difficulty in longitudinal ageing research using self-report measures, with those who maybe experiencing deteriorating cognitive functioning is that the persons perception of the questions to differ from that of first measurement. This has the potential to threaten the internal validity of the design. Being able to control for cognitive functioning at baseline may be a way to mitigate this difficulty.

Another way to mitigate the difficulty of measuring quality of life in those who may have cognitive impairments is to use proxy reports. These are usually obtained by a close relative or caregiver of the individual being assessed. Proxy reports can circumvent any barriers to completion that the individual may have. Researchers comparing proxy and self-report assessments of quality of life find that proxy raters consistently rate quality of life lower than the affected individuals do (Logsdon et al., 2002b; Ready et al., 2004). This may be due to proxy ratings neglecting the underlying affective and cognitive processes that mediate the person's perception of quality of life; influenced by the proxy's own experiences, expectations, beliefs and personality, the relationship with the person and their own level of psychological health, (e.g.,

depression). It may also be due to the person with difficulties finding new meanings in life and perceiving it to be valuable, which might be ignored by proxies (Ettema et al., 2005).

Whilst there are hypothetical links about the role of cognitive functioning and quality of life, (Isen, 2002; Jones et al., 2003; Llewellyn, Lang, Langa, & Huppert, 2008b) many studies fail to find an association between the two and often other factors involved in the concept of quality of life tend to have predominance over cognitive functioning. Below, in Table 18 a number of studies are presented that show the association between quality of life and cognition in both clinical and non-clinical groups.

Study	Sample	Average age	Cognitive measures	Quality of life measures	Major findings
<b>Clinical Groups</b>					
(Kwa, Limburg, & Haan, 1996)	129 Stroke survivors	63.2	Computerized Cambridge Automated Neuropsychological Test Battery (CANTAB)	Visual Analogue Scale (rating QoL on a scale)	Cognitive functioning was not a significant explanatory power on patient's quality of life. Disturbed global functional health, larger volume of infarcts and severity of aphasia were significant independent explanatory factors for poorer quality of life
(Slawek et al., 2005)	100 Parkinson's Disease	66.04	Mini Mental State Examination (MMSE)	Parkinson's Disease Questionnaire (PDQ-39)	MMSE did not predict quality of life ratings
(Ready et al., 2004)	79	60-91	MMSE	Dementia Quality of Life scale (DEMQOL)	Self-rated quality of life did not differ significantly across three groups Neuropsychiatric symptoms were the most consistent predictors of quality of life (psychological and behavioural problems)
(Banerjee et al., 2006)	101 people with dementia and 99 family caregivers	78.7 (dementia) 67.5 (carers)	MMSE	Dementia Quality of Life (DEMQOL)	Quality of life was not statistically significantly associated with cognition or carer age. Psychological and behavioural disturbance and patient age were significantly associated with quality of life.
(Ritsner, 2007)	62 people with chronic schizophrenia	36.9	Computerized Cambridge Automated Neuropsychological Test Battery (CANTAB)	The Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q) and the Quality of Life Scale (QLS)	Deficits in executive functioning, attention, memory and motor skills substantially contributed to predicting impairments in quality of life appraisals.
(Selwood, Thorgrimsen, & Orrell, 2005a)	40 people with dementia	81.5	MMSE	Quality of Life- Alzheimer's Disease (QoL-AD, EuroQoL-5 Domain (EQ-5), DQoL	Decline in subjective quality of life is not inevitable despite a reduction in independence and cognitive ability over time.
Non-clinical groups					

Table 18: Clinical and non-clinical studies investigating the association between cognitive functioning and quality of life

(Padoani et al., 1998)	220 Non-demented elderly	65-85 years	MMSE	WHO/EURO Self - perceived quality of life (LEIPAD)	Significant relationship between MMSE level and quality of life judgements (stronger than the one with age and educational level). Awareness of significant somatic problems influences the subscales, reducing the role of cognitive performance in favour of educational level.
(Konagaya, Watanabe, Ohta, & Takata, 2009)	12,059 community	71.87	Telephone Inventory of Cognitive Status (TICS)	Daily activity, satisfaction with: health, human support, economic state, symptoms of depression and positive mental attitude	Cognitive functioning had more influence on quality of life scores than gender or age
(Llewellyn et al., 2008b)	11,234 community	50 +	MMSE and learning, prospective memory, verbal fluency, numerical ability, cognitive speed and attention	Control/Autonomy, Self- Realization and Pleasure (CASP-19)	Well-being was significantly associated with performance in all individual cognitive domains in linear regression models that were adjusted for depressive symptoms, age, sex and education. Those in the 5 <sup>th</sup> quintile of psychological wellbeing scored an average of 3.0 standard deviations higher on the global measure of cognitive function than those in the lowest quintile.
(Jones et al., 2003)	129 community	75.4	Consortium to Establish a Registry for Alzheimer's Disease (CERAD)	SWB via life satisfaction, positive affect and negative affect	Higher scores on CERAD linked to higher QoL, but mediated through positive affectivity, perceived health and physical health. Cognitive functioning was positively related to life satisfaction and pleasant emotions independent of education and income.

The table highlights that there are mixed results. In clinical groups there is less relationship between cognitive functioning and quality of life than in non-clinical groups. In both sets of sample groups associations are often reduced in significance due to other variables that are known to influence both quality of life and cognitive functioning.

The reasons for finding minimal associations between cognitive decline and quality of life are varied and it has been postulated that: people with cognitive impairment may downgrade the importance of these abilities and place more importance on other life domains that are not impaired (Ready et al., 2004) and show more optimism and resiliency about their situation than others (Ready et al., 2004; Thorgrimsen et al., 2003). It is possible that the nature of quality of life changes depending on the stage of cognitive impairment; that is, what seems important to quality of life in early stages, (e.g., preservation of intellectual capacity) may seem unimportant in late stages, (e.g., when safety and comfort may take on primary importance), (Logsdon et al., 2002b). In a study by Thorgrimsen (2003) people with dementia seemed more optimistic about their quality of life than their carers and managed to 'make the best of it' and 'take one day at a time'. Ready et al., (2004) also supported this and suggested that informants may witness the losses experienced by patients and assume that they are a source of distress. Optimism shown by those with cognitive impairments was not associated with an inability to reflect insightfully about their situation (as rated by an experienced clinician on the Clinical Insight Rating Scale which measures awareness of situation, memory deficit, functional deficits, and disease progression) (Ready et al., 2004), or in their ability to complete the quality of life assessment (Logsdon et al., 2002b). It is possible that higher ratings of quality of life in those with dementia suggests potential resiliency in the face of cognitive impairment and when functional and psychological impairments are present they impact quality of life more so than cognitive functioning.

It is possible that some of the above studies used inappropriate analogues for cognitive functioning e.g. only 2-6 items (Avis et al., 1996; Ringdal & Ringdal, 1993; Wu et al., 1991). Studies using the MMSE, (Banerjee et al., 2006; Ready et al., 2004; Selwood et al., 2005a) show

differing results; which may reflect the limited ability of the MMSE to cover all cognitive domains relevant to quality of life for different populations. Studies that use more sensitive, broad and valid measures of cognitive functioning often do find a relationship between cognitive function and quality of life (Jones et al., 2003; Padoani et al., 1998).

Overall, the findings suggest that quality of life and cognitive functioning do have a relationship but it is weak in comparison to the relationship between quality of life and physical and psychological health. The relationship between cognition and quality of life also appears to be mediated by these other factors. In younger population groups, cognitive functioning appears to impact on quality of life but as people age this decreases as other factors take on more importance (e.g., social and health functioning).

Other research has investigated the potential improvement of cognitive function and the flow on effects to quality of life. In a study of older adults with Alzheimer's Disease it was found that although cognitive functioning was not associated with quality of life at baseline, after cognitive stimulation therapy, (grounded in creating a strong value base of respecting individuality and personhood), there was an improvement in quality of life, (memory, energy, relationships and managing chores) with an associated increase in cognitive functioning. Changes in cognitive function mediated the effects of treatment in improving quality of life. This suggests that quality of life in Alzheimer 's disease may be independent of cognitive function but that interventions to improve cognitive functioning can have a direct effect on quality of life (Woods et al., 2006). Furthermore, cognitive enhancing medication given to people showing MCI led to a subsequent increase in cognitive functioning, (measured with MMSE) and improved quality of life (Mila, Podea, & Chenderes, 2009). So while cognitive functioning appears to be independent of quality of life, improvements in cognition can lead either directly or indirectly to improvements in quality of life. Therefore, monitoring change in quality of life with people who show progressive cognitive decline may suggest new areas of cognitive intervention to help maintain or enhance life quality. Quality of life can therefore be used as a measure of change after an intervention to determine whether a cognitive intervention is providing clinically significant benefits (Padoani et al., 1998).

#### Conclusions

The research to date around the conceptualization and definition of quality of life is immensely varied, which is reflected in the wealth of quality of life measures based on differing conceptualisations of quality of life and different population groups. As people age there tends to be a change in the relative importance placed on different facets of quality of life which means that quality of life measures need to be tailored for this population. Despite potentially poorer physical, psychological and social functioning, older adults are showing resilience and adaptation, and maintaining their quality of life well into their 80's. Even in the face of cognitive impairment which can impact the very facets that predict quality of life, older adults are maintaining quality of life. In larger community based studies, assessment of older people with age appropriate quality of life measures, often finds that cognitive functioning does show a predictive relationship with quality of life, however the strength of the association and the influence of specific cognitive domains on quality of life is unclear. Many of these studies use poor measures of cognition which are not sensitive enough to impairments and are not domain specific (e.g., MMSE) and quality of life measures that are narrow and not sensitive to the important domains of quality of life in older age. There is a need to consider a life course approach to the conceptualization and measurement of quality of life and measure a wide variety of factors pertaining to quality of life, not just health. Measures of quality of life need to capture the diverse factors noted as important in older age conceptualization of quality of life.

In the next section a manuscript for publication is presented which attempts to address these issues by analysing the influence of cognitive performance assessed objectively through administration of the Addenbrooke's Cognitive Examination-Revised on the subjective perception of quality of life, in a sample of community dwelling older adults. The aims of the study are to answer the following questions:

- Are there specific cognitive domains that impact quality of life more?
- How much variance in quality of life scores does cognitive functioning explain?
- o Does level of cognitive functioning impact on ratings of quality of life?
- What else explains the variance (e.g., psychological, physical and social factors)?

# Study Three: The Relationship between Quality of Life and Cognitive functioning in Community Dwelling Older Adults in New Zealand

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## Abstract

The Aristotelian concept of a 'good life' is not only something to live for but also to live by. This is even more so in older ages where longer living is often described in terms of strategies for maintaining quality of life in the face of increasing adversities. Older adults have a unique perspective on what factors are important to quality of life and this is investigated in relation to the unique contribution that cognitive functioning has in affecting quality of life ratings. A nationwide sample of 1005 New Zealanders aged 45+ were assessed using the Addenbrooke's Cognitive Examination – Revised and quality of life measures: The CASP, World Health Organization quality of life scale and the Short Form-12. Results found that in the overall sample quality of life and ACE-R scores were minimally associated.

# Introduction

Despite the concept of quality of life having its beginnings more than two millennia ago by Aristotle, only in the last 60 years or so has there been an upsurge in the literature on the topic (Testa & Simonson, 1996a). The upsurge was in part due to the changing definition of health, with the World Health Organization defining health as being not only the absence of disease but also the presence of physical, mental and social well-being (World Health Organization, 1946). The more holistic view of health has solidified the idea that adding life to years is as important as adding years to life. The exponential increase in the use of quality of life as an outcome measure had helped in clinical research to assess and measure changes in physical, functional, mental and social health (Testa & Simonson, 1996a). This information can be used to show which factors are the most important for maintaining quality of life, implementing strategies, monitoring change, evaluating interventions and influencing social policy.

Quality of life is highly individualistic and subjective and may be an 'idiosyncratic mystery' due to the variability between individuals (Netuveli & Blane, 2008). It can be argued that within societies there are common core values that influence overall quality of life, but because it is also subjective, it is equally dependent upon the interpretations and perceptions of the individual (Gabriel & Bowling, 2004). As such, the definition and measurement of quality of life should be grounded empirically in lay views, and should reflect the individual subjectivity and difference in the concept, whilst taking into account the wider social circumstances.

The quality of life concept is complex and elusive with numerous theoretical underpinnings and ways of measuring it (Logsdon, Gibbons, McCurry, & Teri, 2002a). As such, there is little consensus around the meaning of the term and there is a trend towards divergence. Often it is the researcher's conceptual orientation and context in which it is used which determines how quality of life is defined and measured, (Logsdon et al., 2002a); hence why a decade ago it was noted that there are over 1000 measures of the construct, (Thorgrimsen et al., 2003). Lawton et al., (1999b) developed a quadripartite concept of quality of life that accounted for the multiple influences on quality of life. He proposed that the 'good life' (i.e., quality of life) could be represented by behavioural and social competence (health, cognition, time use, social behaviour), perceptions of quality of life (subjective evaluation of each domain of life), psychological well-being (mental health, cognitive judgements of life satisfaction, positive-negative emotions) and the external, objective, physical environment (housing, economic indicators). This model encapsulates a multidimensional construct of quality of life but still has no theoretical grounding or identifiable way to measure it (Bowling & Stenner, 2010). Ultimately quality of life in his model is decided by psychological wellbeing and all that comes before that could be considered as influences on it (Netuveli & Blane, 2008). Despite drawbacks in the conceptualization it is one of the most influential conceptualizations, particularly in research with older people.

One well used definition which captures a number of the dimensions of quality of life suggested by Lawton is that given by the World Health Organization (WHO). Quality of life was defined as:

"An individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment" (World Health Organization, 1995, p. 2).

This definition covers physical wellbeing, (self-sufficiency, illness symptoms, mobility), psychological wellbeing, (emotions, behaviour, cognitive status) and social wellbeing, (one's role in relation to others), (The WHOQOL Group, 1994). This definition reflects the view that quality of life is a subjective evaluation embedded in a cultural, social and environmental context. It provides a starting point in knowing what to look at when assessing quality of life, but it also leaves unanswered questions. For example, what other areas should be included in addition to the physical, mental and social ones? Should the measurement include objective characteristics of the individual as well as their own subjective evaluation? Answering these questions goes beyond the scope of the current research but deserves attention as it highlights the complexity of quality of life.

# Quality of life in older age

Due to the demographic shift and the increasing numbers of older people, (Statistics New Zealand, 2012) there is a policy initiative in New Zealand to enhance older adults' quality of life and to try to increase their independence and ability to live and function well in their communities, (e.g., the ageing in place strategy, Ministry of Social Development, 2001). Having good quality of life is known to improve health and promote positive ageing (Gabriel & Bowling, 2004) and therefore it is an important concept to be recognised in the ageing literature and in social policy.

Research suggests that quality of life changes with age. It would be expected that due to the natural losses and difficulties associated with older age that quality of life would inevitably be reduced as people age because the very factors that are known predictors of quality of life can also be consequences of ageing. For example, quality of life can be effected directly by age, (e.g., through physical health difficulties or cognitive functioning decline) or indirectly through the effect of ageing on factors that influence quality of life, (e.g., loss of social supports through natural death, reduction in independence), (Netuveli & Blane, 2008). However, the literature does not support this assumption. Studies of quality of life across age groups generally find that quality of life is maintained into older age (Buono, Urciuou, & de Leo, 1998; Daatland, 2005; Netuveli & Blane, 2008; Netuveli, Wiggins, Hildon, Montgomery, & Blane, 2006a; Zaninotto, Falaschetti, & Sacker, 2009), contrary to many of the stereotypes of old age. However, some longitudinal studies find that quality of life drops with age (Zaninotto et al., 2009) suggesting that a life-course approach to understanding the relationship between ageing and quality of life is required.

Quality of life ratings are variable depending on what life stage people are at and the relative importance of factors that contribute to quality of life tend to change. Bowling and colleagues (2003) asked 999 people aged 65 years older about their views on quality of life. Factors that enhanced quality of life were: having good social relationships with children, family, friends and neighbours; neighbourhood social capital represented by good relationships with neighbours, nice and enjoyable neighbourhood, comfortable houses and good public services such as free transport facilities; psychological factors such as optimism and positive attitude, contentment, looking forward to things, acceptance and other coping strategies; being actively engaged in social activities such as attending educational classes and volunteering; good health; financial security which brought enjoyment as well as empowerment and having to not depend on others. Subjective ratings in this study were more strongly associated with quality of life than objective variables (e.g., social-economic status). This is similar to a Swedish study with living in your own home and social relations being the most important for quality of life (Wilhemson, Andersson,

Waern, & Allebeck, 2005). In New Zealand, common themes of quality of life in older adults revolves around: good people, independence at home and meaningful contribution to the community. Poorer quality of life was linked to poor personal health (Hambleton et al., 2008)

These reviews show that, in older age quality of life clearly goes beyond objective measures of finances and living conditions and that it is the perspective people have about these factors, and particularly social relationships and health that becomes more important.

# Cognition and quality of life

Surprisingly few studies have investigated the effects of cognitive functioning on quality of life, despite it being listed as a psychological factor and health in well-known conceptualizations and definitions of quality of life (Lawton & Powell, 1991; World Health Organization, 1995). Additionally, a number of factors known to influence cognitive functioning (e.g., depression, perceived social support, physical health, education and age (e.g., depression, perceived social support, physical health, education and age, Anstey & Christensen, 2000; Bierman, Comijs, Jonker, & Beekman, 2005a; Butler et al., 2004) are also known factors that influence quality of life (Daatland, 2005; Farquhar, 1995; Lawton & Powell, 1991).

Cognitive skills such as: perception, information processing and memory, can play a substantial role in determining what aspects of the environment we attend to and how this information is assimilated into our memories. For example, recalled information is subject to modification through previous stored information and by new and existing inputs; therefore construing what is recalled to conscious attention (Lawton & Powell, 1991). Any stimulus may modify the individual's construction of their quality of life at any of these levels (Netuveli & Blane, 2008). Even the way in which a quality of life questionnaire is filled in involves cognitive skills (e.g., do people compare themselves to others to determine their quality of life, are their answers biased by poor memory and so on). Furthermore, cognitive functioning ability can influence the overall

validity of the assessment through the influence of cognitive fallacies which may affect the quality and accuracy of responses (Katschnig, 2006)

Hypothesized mechanisms for the relationship between quality of life and cognitive functioning include:

- Good cognitive functioning may enhance quality of life through improved adaptation, resilience and independence (Netuveli & Blane, 2008) or interaction with society (Ahlsio, Britton, Murray, & Theorell, 1984b).
- Conversely, deteriorating levels of cognitive function might also lead to reduced levels of quality of life through loss of independence and ability to adapt to change (Padoani et al., 1998), stress and isolation (Ahlsio, Britton, Murray, & Theorell, 1984a).
- Enhanced quality of life may make socializing, intellectual and physical activities more likely and reduce stress, which may in turn influence neural efficiency and levels of cognitive function (Scarmeas & Stern, 2003). Additionally a good quality of life may induce positive mood states which can enhance cognitive performance over short periods (Isen, 2002) and long periods of time (Llewellyn et al., 2008a).
- Low levels of quality of life may decrease cognitive functioning through fewer opportunities for stimulation (Bennett et al., 2006)

These hypotheses remain largely untested and represent a significant gap in the research. Surprisingly few studies have evaluated the effects of cognitive health on quality of life among normal older individuals (Jones et al., 2003). Many population based gerontological studies exclude people with cognitive impairment or those taking medications that might alter cognitive status, thereby limiting the generalizability of the sample and reducing the ability to make valid conclusions (Jones et al., 2003).

Large community based studies that investigate cognitive functioning and quality of life tend to show associations between the two constructs. Partial correlations (adjusting for age, gender and education) were seen among scores on the Telephone Inventory of Cognitive Status and a quality of life questionnaire (based on Lawton's conceptualization) in a large Japanese study (Konagaya et al., 2009). In a large English longitudinal study assessment of psychological well-being, (one aspect of quality of life, measured by the CASP) and cognitive functioning, (time orientation, immediate and delayed verbal memory, prospective memory, verbal fluency, numerical ability, cognitive speed and attention), it wasfound that those in the fifth quintile of psychological wellbeing scored an average of 0.30 standard deviation units higher on the cognitive measures, than those in the lowest quintile (after controlling for confounders such as depressive symptoms and socio-demographics) (Llewellyn et al., 2008a). The difference in cognitive function between those in the highest and lowest 'well-being' quintiles was equivalent to the decrement in cognitive function associated with four additional years of age.

In a smaller study (n=129) cognitive functioning was modestly associated with life satisfaction and positive affectivity; however, perceived health and physical health showed stronger relations to wellbeing outcome than cognitive functioning status (Jones et al., 2003). The researchers suggested that cognitive functioning played a unique role in wellbeing through the enhancement of positive emotions; suggesting that people with good cognitive abilities are better able to appreciate subtle positive aspects of living and utilize available resources, or adapt to circumstances, in a manner which enhances wellbeing.

Studies looking at those who already experience cognitive difficulties, (e.g., dementia) have found that quality of life either does not decline over time (Selwood, Thorgrimsen, & Orrell, 2005b), remains unchanged or can increase (Lyketsos et al., 2003); this was independent of clinician rated insight into cognitive difficulties (Logsdon et al., 2002b). A decline in subjective quality of life is not inevitable despite a reduction in independence and cognitive ability over time. It seems that people with dementia are able to adapt to this and continue to have positive experiences. In a study of people with schizophrenia it was found that deficits in executive functioning, attention, memory and motor skills substantially contributed to predicting impairments in a number of

health-related quality of life domains (Ritsner, 2007). Different age groups and different ways of assessing quality of life may be attributable to different results.

Other studies show that while cognition is related to quality of life, there are other factors that show a stronger association, such as: depression and anxiety (Benerjee & Wittenberg, 2009), functional decline (Thorgrimsen et al., 2003) and behavioural and psychological disturbance (Banerjee et al., 2006). A further study suggested that it was the perception of somatic aspects of health that mediated the relationship (Padoani et al., 1998). Therefore, cognitive functioning and quality of life associations may be mediated by other processes such as affect, perceived health and functional ability.

As the studies presented have shown, older adults are showing resilience and adaptation to the challenges that come with ageing, to the point where the conceptualization of quality of life changes and relative importance is placed on different facets of life. Cognitive functioning and quality of life do appear to have a small and significant relationship, however, the direction of the relationship and the extent to which it is mediated by other factors is unclear. Due to the cross-sectional nature of the current research these questions can not be fully addressed, however this research can provide a baseline for these questions to begin to be answered in future longitudinal research using the same sample.

The aims of the current study were to investigate the relationship between cognitive functioning and quality of life through the following research questions:

- Are there specific cognitive domains that impact quality of life more?
- o Does cognitive functioning impact different factors of quality of life?
- Does having lower cognitive functioning make a difference in quality of life scores to those with average or high cognitive functioning?

 Does cognitive functioning explain variance over and above factors that are known correlates (e.g., those mentioned in Lawton's conceptualization such as psychological, social or physical health.

## **METHOD**

## Participants

The current sample of 1005 participants was drawn from a population sample collected as part of the New Zealand Longitudinal Study of Ageing (NZLSA). NZLSA expands on the earlier Health, Work and Retirement study (HWR) which recruited a representative sample of older New Zealanders from the New Zealand electoral roll in 2006 aged 55 to 70 years. In 2010 the sample was expanded to include younger and older age groups (ranging from 50-84) and became the New Zealand Longitudinal Study of Ageing (NZLSA); a population-level study. The NZLSA had two specific objectives: (1) to establish a nationally representative longitudinal study of the health, wealth and social factors that contribute to positive ageing in New Zealand, and (2) to compare the data gathered with that of similar studies in Australia, UK, the USA and Europe in order to best inform public policy and practice from an international perspective. The specific aims of NZLSA are to make observations and test hypotheses about the contributions to ageing people's quality of life within four broad areas: economic participation (e.g., meaning of work, employment, retirement); social participation (e.g., family support, social capital, civic participation); intergenerational transfers (e.g., family care, income, wealth and knowledge); resilience and health (e.g., control, coping, physical, emotional, cognitive).

A total pool of 4,339 older New Zealanders were invited to participate in the first NZLSA postal data collection wave in 2010, and comprised (1) HWR participants who participated in the 2008 data collection wave, (2) HWR participants from 2006 who consented to re-enter the study, (3) participants from a related cross-sectional study of retirement planning at Massey University, (4) participants from a pilot study conducted on the NZLSA survey questionnaire, and (5) New Zealanders randomly selected from the New Zealand electoral roll to increase the numbers of

respondents at the younger (i.e., 50-54) and older (i.e., 70-84) age groups. Māori over-sampling was specifically undertaken during participant selection for NZLSA. A total of 3,312 (76%) from the pool completed NZLSA Wave 1 questionnaires (2010). For more details see Alpass et al., (2007).

The current sample was recruited through the NZLSA database from people who volunteered to have face to face interviews. The present sample study is comprised of 1005 participants; 47.6% male and 52.4% female. Age ranged from 48-83 years with a mean age of 61.9 (7.79). Participants were grouped into four age brackets for normative purposes. Those above 75 years and over (n= 105), those aged from 65 to 74 years (n=105), those aged from 55 to 64 years (n=369) and those aged below 55 years (n=298). A large percentage were well educated, having either tertiary education (n= 222, 22.1%) or at least post-secondary or trade qualifications (n=366, 36.4%). Over half the sample were married (n=630, 62.6%) and the majority of the sample described themselves as New Zealand European (n=883, 87.8%). Table 19 compares the participants' demographic data with that of the census data from 2006.

	% NZLSA sample aged 45-84, N=1005	% General population (2006) aged 45-84, N=1,453,194
Sex		
Male	45.6	47.6
Female	54.1	52.3
Age		
45-54	29.7	38.4
55-64	36.8	30.0
65-74	22.9	19.4
75-84	10.6	12.2
Primary Ethnic Group Affiliation		
Pakeha/New Zealander or European Decent	86.2	71.1
Māori	7.6	7.6
Pacific Island	0.6	3.2
Asian	1.9	5.5
Other	3.7	12.6
Marital Status		
Married	63.4	59.9
Civil Union/De facto	6.9	-
Same Sex Civil Union/De Facto	1.5	-
Divorced/Separated	11.1	14.9
Widow or Widower	11.0	11.7
Single	5.7	7.2
Missing	-	6.3
Highest Qualification		
No Qualifications	17.4	37.2
Secondary School	22.4	27.9
Post-Secondary /trade	36.4	25.4
University Degree	22.1	10.0

Table 19: Characteristics of NZLSA Weighted Face To Face Study Population Compared to General Population Using Census Data From 2006

The current sample represents 0.05% of the total New Zealand population aged over 45 years. HWR and NZLSA over-sampled for Māori and a post-stratified weighting variable was calculated to account for known discrepancies between the sample and the population. Compared to the general population aged over 45, the current sample that volunteered were more highly educated, were over-sampled in the 45-54 age group and had a greater proportion of 55-64 age group. Pacific Peoples and Asian ethnic groups were under represented. Overall this sub-group is generally representative of the targeted population and norms generated from this sample are likely to be representative of older New Zealanders.

#### Procedure

Face-to-face interviews were conducted nationwide with a voluntary subset of the 2010 postal survey responders (N=1005) who resided independently in the community. Participants were interviewed in their own home. Interviewers were given specific training in administering questionnaires and tests, with adherence to test manual instructions.

#### Materials

Participants completed a number of questionnaires that included standard demographics and measures of quality of life, cognition, economic stability, physical health, depression symptoms, neighbourhood services, sense of safety, supports, abuse, work and income, retirement expectations, income, assets, loneliness and discrimination. The main ones are presented here and the ones used less in the analysis are provided in Appendix F.

#### Addenbrooke's Cognitive Examination Revised (ACE-R, Mioshi et al., 2006a).

The ACE-R is a cognitive screening measure for dementia. It was developed originally in 2000 (Mathuranath et al., 2000) and revised in 2006 (Mioshi et al., 2006a). It was developed as an improvement on the Mini Mental State Examination (MMSE, Folstein et al., 1975) with lower ceiling effects (expanding the points available), improved sensitivity, and assessment of more cognitive domains, particularly components for memory and frontal/executive functioning (Mathuranath et al., 2000). Extra non-MMSE items improve estimates of cognitive ability by 16% compared to the MMSE (Law, Connelly, Randall, 2012). The ACE-R was developed and normed in the United Kingdom. It includes norms for clinical and non-clinical populations, (e.g., cognitively impaired or a control group). The ACE-R has good psychometric properties, with very good internal consistency, ( $\alpha$ =0.80) and significant concurrent validity, (as measured by the correlation coefficient between the ACE-R and the Clinical Dementia Rating Scale, Pearson's *r*=0.32). No significant age or education effect on scores were found (Mioshi et al., 2006a). The measure includes items assessing the cognitive domains of: attention and orientation (e.g., what is the date?), fluency (e.g., naming words beginning with F), language (e.g., writing sentences and

repeating words), visuo-spatial (e.g., copying a pentagon and drawing a clock face) and memory (e.g., short term, long term, anterograde and retrograde tasks). There are a total of 100 points available across the five domains and it takes 10-15 minutes to administer. A normative study of the ACE-R using the current sample found a mean score of 93.7 and standard deviation of 5.07, (see previous article).

## Quality of life

To capture the multi-dimensionality of the concept a number of quality of life measures were used. The World Health Organization quality of life measure (WHOQOL) and the Short Form-36 (SF-36) provide the basis for quality of life measurement in over half of the national surveys of quality of life (Schmidt, Mühlan, & Power, 2006). The Control, Autonomy, Self-realization and Pleasure scale (CASP) is a specific measure developed to assess the quality of life of older people. These three quality of life measures are widely used, well validated and used in other longitudinal studies such as the WHO Study of Global Ageing (SAGE), English Longitudinal Study of Ageing (ELSA) and the Survey of Health, Ageing and Retirement in Europe (SHARE).

## World Health Organization Quality of Life-8 (WHOQOL-8)

WHO's initiative to develop a quality of life assessment arose, from a need to reinstate its commitment to the continued promotion of a holistic approach to health and health care, as emphasised in the WHO definition of health as "A state of physical, mental and social well-being, not merely the absence of disease and infirmity", (World Health Organization, 1998, p. 11). The World Health Organization group have developed a range of versions of the World Health Organization quality of life scale (WHOQOL); thought to assess these aspects; focusing on people's 'perceived' quality of life rather than measuring symptoms, disease or conditions.

The most recent scale developed was the WHOQOL-8 (Power, 2003) which was designed for use where researchers needed a short and concise quality of life instrument. It is an 8-item index, derived from the WHOQoL-100 and the WHOQoL-BREF. The overall quality of life score is

formed by a simple summation of scores on the eight items. All answer scales have a 5-point response format on a Likert scale, ranging from 'not at all' to 'completely'; with higher scores indicating better quality of life (scored 0-40). Each domain (psychological, physical, social and environmental) is represented by two items. Examples include: "How would you rate your quality of life?" (Very poor, poor, neither poor nor good, good, very good) and "Do you have enough energy for everyday life?" (Not at all, a little, moderately, mostly, completely). In a survey of European adults (n=4, 849), (Schmidt et al., 2006) the 8 item index was assessed across 10 countries with equal samples and adjusted for selected socio-demographic data. Findings indicated good internal consistencies, acceptable convergent validity and a universal one-factor structure. The scale showed a good correlations between other measures such as the mental health indexes (MHI5, r = 0.49), general health variable (Short Form-12, r = 0.53) and social support (Oslo Social Support Scale, r = 0.36).

## Short-Form- 12v2 (SF-12v2)

In order to make provision for indicators relating to subjective health quality of life, Ware and Sherbourne (1992) developed a 36-item short-form (SF-36) questionnaire measuring physical and mental health constructs "...for use in clinical practice and research, health policy evaluations, and general population surveys" (Ware & Sherbourne, 1992, p. 473). The SF-36 is the most widely used global measure of health-related quality of life (Schmidt et al., 2006) and assesses the person's experiences, feelings, beliefs, perceptions and convictions concerning their health-related quality of life during the past four weeks. The SF-12v2 is a shorter form than the original SF-36 and shows comparable reliability and validity to the original scale (Ware et al., 1996a). The Short Form-12 provides two summary scores; a physical component summary (PCS) and mental component summary (MCS) yielded from eight subscales, one for each conceptual domain. There are two questions each for the scales: physical functioning, (the extent to which the respondents' perceptions of their quality of life are influenced by their physical condition), physical roles (the

extent to which respondents' performance of their roles in daily activities is impeded by their physical state of health), mental health (extent to which respondent is feeling full of pep, is happy, is feeling calm and peaceful, is very nervous, or is feeling worn out and tired), emotional role (the extent to which the emotional condition of the respondent, e.g. feeling depressed or anxious, limits his/her daily functioning and ability to perform roles). There is one question each that assesses: bodily pain (extent the respondents' experience of bodily pain hinders their performance of daily activities), social functioning (refers to social activities and interaction with significant others such as family members, friends, neighbours and other social relations), vitality (relates to the respondent's experience of feeling energetic and full of pep, or worn out and tired) and general health perception (measured in terms of concepts such as excellent, very good, good, fair or poor, getting ill easier than other people, and just as healthy as anyone he/she knows).

The two component scores derived are scored from 0-100 and standardized with a mean of 50 and standard deviation of 10 (norm-based scoring). It takes an average of two minutes to complete and shows good test-retest reliability (0.76-0.89), discriminatory power, construct validity (0.95-0.96) and adequate sensitivity to change (Resnick & Nahm, 2001; Ware, Kosinski, & Keller, 1996b).

#### Control, Autonomy, Self-realization and Pleasure scale (CASP-12)

It has been argued that the above measures do not capture the full extent of *quality of life* within *older* populations and do not account for the range of experiences that older people have been through (Wiggins et al., 2008). *The CASP-12*, a self-report questionnaire of quality of life, was developed to address these issues (Hyde, Wiggins, Higgs, & Blane, 2003b). The measure has its theoretical underpinnings in Maslow's hierarchy of needs (Maslow 1970). The domains within the CASP are: Control (freedom from)/Autonomy (freedom to), Self-realisation and Pleasure; basic human needs. It is particularly relevant to the third age of life believed to be a period of life in which self-development and self-realisation can be given priority. These domains recognise the vulnerability of the sense of self in later life, with accelerating social change, and increasing social differentiation and complexity (Blane, Higgs, Hyde, & Wiggins, 2004). The use of CASP-12

allows measuring of quality of life directly, without relying on proxies such as health status or level of social participation; hence it has the ability to distinguish between quality of life and the factors that may influence it.

The CASP has been adopted by several important studies, notably the English Longitudinal Study of Ageing (Marmot et al. 2003), the retirement module in wave 11 of the British Household Panel Survey (Taylor 2003), the Survey of Health, Ageing and Retirement in Europe (SHARE) and the Irish Longitudinal Study of Ageing (TILDA).

The domains are assessed across 12 items which are scored on a four point Likert-scale of agreement, (e.g., 'I look forward to each day'- never, not often, sometimes, often) with total scores ranging from 12-42. The CASP-12 has reported psychometrics suggesting alphas between 0.6 and 0.8 and a strong and positive correlation between other quality of life measures (e.g., Life Satisfaction Index), (Hyde et al., 2003b).

## RESULTS

#### Data analyses.

All statistical analyses were conducted using the Statistical Package for Social Sciences, SPSS (version 20.0, Chicago, IL). Pearson's correlations were used to assess the direction and strength between variables. Partial correlation was used to control for variables with shared influence. Student T-tests and Analysis of Variance (ANOVA) were used to test for differences between groups, and where significant, post-hoc analyses were used to explore differences between sub groups. Effect sizes were calculated using eta,  $\eta^2$ .

## Reliability and validity.

Chronbach's alpha measuring internal consistency was performed for each quality of life measure. Alpha was derived from single items of the WHOQOL-8 ( $\alpha$ =0.90), the three domains of the CASP-12 ( $\alpha$ = 0.76) and the eight standardized domains of the SF-12v2, ( $\alpha$ = 0.87). Each

quality of life measure showed acceptable alpha levels, suggesting that the constructs showed excellent reliability. These alpha levels are similar to those reported in other studies (Hyde et al., 2003b; The WHOQOL Group, 1994; Ware et al., 1996b)

Table 20 shows two-tailed bivariate Pearson correlations between the quality of life measures. For purposes of interpretation, correlations 0-0.24 are considered small, 0.25–0.50 are considered modest, whereas correlations greater than 0.50 are considered large (Cohen, 1988). Results found significant small to large correlations suggesting that the measures show good concurrent validity.

Measure	WHOQOL -8	SF-PCS	SF-MCS	CASP-12	CASP-12 Self-	CASP-12	CASP-12 Pleasure
						Autonomy &	rleasure
					Realization	Control	
WHOQOL -8	3 1.00	0.52**	0.54**	0.77**	0.72**	0.71**	0.51**
SF-PCS		1.00	0.13**	0.40**	0.42**	0.41**	0.11**
SF-MCS			1.00	0.52**	0.50**	0.41**	0.44**
CASP				1.00	0.88**	0.90**	0.76**
CASP-12 Sel	f- Realization				1.00	0.64**	0.65**
CASP-12 Aut	tonomy & Control					1.00	0.50**
CASP-12 Plea	asure						1.00

Table 20: Pearson Correlations (r) between quality of life Measures and sub-domains.

\*\*Correlation is significant at p<0.01

#### Quality of life Scores.

Each quality of life measure has a different scoring criteria and minimum/maximum scores

available. Scores on the quality of life measures are provided in Table 21.

Table 21: Means, Standard Deviations and Minimum, Maximum Scores for the Quality Of Life Measures (n=1005)

Quality of life Measure	Mean (SD)	Minimum	Maximum
(score range)			
WHOQoL-8 (0-40)	32.66 (5.70)	8.00	40.00
SF-12 (0-100)			
Physical	48.32 (10.70)	10.21	68.22
Mental	52.90 (8.77)	12.68	69.61
CASP-12 (12-42)	40.32 (5.52)	14.00	48.00
CASP-12 Autonomy & Control	25.05 (2.98)	14.00	30.00
CASP-12 Pleasure	20.23 (1.42)	12.00	21.00
CASP-12 Self-Realization	19.06 (2.00)	12.00	21.00

#### 'Kiwi' ACE-R association with quality of life and quality of life domains

Table 22 shows the two-tailed bivariate Pearson correlations between 'Kiwi' ACE-R score and quality of life measures. Results showed that ACE-R score was positively associated with the WHOQOL-8, SF-PCS and CASP-12, (including the sub-domains of Autonomy & Control and Self-Realization). The effect size of these associations ranged from 1-5%. SF-MCS and the CASP sub-domain Pleasure had no association with 'Kiwi' ACE-R score. Socio-demographic factors known to influence cognition were controlled for (age and qualification level) through partial correlations, significant associations remained, but weakened.

Measure	WHOQOL- 8	SF- PCS	SF- MCS	CASP- 12	CASP-12 Autonomy & Control	CASP-12 Pleasure	CASP-12 Self- realization
ACE-R	0.17**	0.24**	-0.03	0.13**	0.12**	0.05	0.14**
Attention/Orientation	0.10**	0.12**	0.05	0.04	0.03	0.03	0.04
Fluency	0.12**	0.19**	-0.04	0.11**	0.08**	0.05	0.16**
Language	0.10**	0.10	-0.04	0.07	0.08**	0.02	0.04
Visuo-spatial	0.08**	0.18**	-0.03	0.10	0.08**	0.06	0.11**
Memory	0.13**	0.16**	0.00	0.08	0.09**	0.03	0.08**

Table 22: Pearson Correlations (r) between 'Kiwi' ACE-R Total and Sub-domain Scores and Quality of Life Measures.

\*\* Correlation is significant at the 0.05 level (2-tailed).

## Amount of variance in quality of life scores explained by the ACE-R

Based on Lawton's conceptualization of quality of life, the main factors that influence quality of life were entered into a hierarchical regression to see what unique contribution cognition had, while controlling for the effects of other variables. Factors entered into the regression included: physical health (number of physical difficulties) and social dimensions, physical, social and economic indicators such as housing or income.

To determine the relative and unique contribution of demographic, health, cognitive, social and psychological measures in predicting quality of life, hierarchical multiple regression analyses were conducted. Tolerance for multicollinearity among the independent variables was within the acceptable range. The results of the analysis explaining variance within quality of life among the different measures are summarised in Table 23. Independent predictor variables were entered as a block (Model 1), with 'Kiwi' ACE-R score entered into the second block (Model 2), to find the unique contribution 'Kiwi' ACE-R (through R<sup>2</sup> change) while controlling for the effects of the other predictor variables. Predictor variables examined are listed below and explained in more detail in Appendix F:

- Participant age
- Highest qualification level
- Number of physical health conditions
- Social support (as measured by the Social Provisions Scale)

- Networks and Neighbourhood (as measured by the Wenger Network Assessment Instrument)
- Economic standing (as measured by the Economic Living Standards Index)
- Anxiety (as measured by the Geriatric Anxiety Inventory)
- Depression (as measured by the Center for Epidemiologic Studies Depression Scale)
- Loneliness (as measured by the De Jong Gierveld Short Scales for Emotional and Social loneliness)

Table 23: Hierarchical Multiple Regression with  $R^2$  Change Explaining the Variance in Quality of Life Scores in Two Different Models

Quality of Life measure		Adjusted R	Std. Error of the	Change Statistics				
	Model Square		Estimate	R <sup>2</sup> Change	F Change	df1	df2	Sig. F Change
SF-PCS	1	.356	8.266	.364	46.474	9	729	.000
	2	.358	8.253	.003	3.180	1	728	.075
SF-MCS	1 2	.412 .412	6.449 6.450	.419 .001	58.557 .740	9 1	729 728	.000 .390
	_					-		
CASP	1 2	.546 .547	3.767 3.767	.552 .001	105.329 1.269	9 1	770 769	.000 .260
	1	(())	2.26	664	160 409	0	770	000
WHOQOL	1 2	.660 .660	3.26 3.26	.664 .001	169.408 1.437	9 1	772 771	.000 .231

Multiple R for the regression with SF-PCS as the criterion variable was significantly different from zero, F (10, 739) =42.27, p<0.00. Together the variables accounted for 36.4% of the variance in SF-PCS. Examination of the R2 change reveals that 'Kiwi' ACE-R adds 0.003, a nonsignificant change to explaining the variance in SF-PCS score. Multiple R for the regression with SF-MCS as the criterion variable was significantly different from zero, F (10, 739)=52.73, p<0.00. Together the variables accounted for 41.2% of the variance in SF-MCS. Examination of the R<sup>2</sup> change reveals that 'Kiwi' ACE-R adds 0.001, a non-significant change to explaining the variance in SF-MCS score. Multiple R for the regression with CASP as the criterion variable was significantly different from zero, F (10, 779) =94.95, p<0.00. Together the variables accounted for 54.7% of the variance in CASP. Examination of the R<sup>2</sup> change reveals that 'Kiwi' ACE-R adds .001, a non-significant change to explaining the variance in CASP score. Multiple R for the regression with WHOQOL-8 as the criterion variable was significantly different from zero, F (10, 781) = 152.69, p<0.00. Together the variables accounted for 66.0% of the variance in WHOQOL-8. Examination of the R<sup>2</sup> change reveals that the 'Kiwi' ACE-R adds 0.001, a non-significant change to explaining the variance in WHOQOL-8 score.

#### Low 'Kiwi' ACE-R scores and ratings of quality of life

Quality of life scores for those who scored above the clinical cut-off for cognitive impairment (n=971) were compared to those who scored below the clinical cut off (ACE-R 82) (n=34). An independent samples t-test was conducted. The Levene's test for equal variance was violated within the WHOQOL-8 and CASP pleasure sub-domain and CASP self-realization sub-domain, so a t-test for unequal variances was used in those analyses. All quality of life ratings were significantly different between groups except for SF-MCS which was non-significant. Table 24 shows that on the WHOQOL-8, CASP (including the sub-domains) and the SF-PCS, participants with lower 'Kiwi' ACE-R scores rated their quality of life consistently lower than those with higher scores on the 'Kiwi' ACE-R. These significant differences remained when age, sex, education, ethnicity and depressive symptoms were controlled for.

Quality of life measure	'Kiwi' ACE-R score	ACE-R N <sup>7</sup> (Standard		T-test of significance	Mean difference in quality of life rating
SF-PCS	Low High	28 909	41.36 (10.44) 48.54 (10.65)	t(934)=-3.49, p<0.00	-7.18
SF-MCS	Low High	28 909	51.54 (12.44) 52.94 (8.64)	t(934)=-0.82, p=0.41	-1.39
WHOQOL-8 Scale score	Low High	34 972	27.63 (7.14) 32.82 (5.57)	t(33.9) = -4.16, p<0.00	-5.19
CASP-12 Scale score	Low High	30 965	36.02 (6.07) 40.45 (5.46)	t(993) = -4.40, p<0.00	-4.44
- Autonomy & Control	Low High	30 965	22.86 (3.08) 25.11 (2.96)	t(993)=-4.12, p<0.00	-2.24
- Pleasure	Low High	31 969	19.26 (1.85) 20.26 (1.40)	t(31.3)=-2.96, p=<0.00	-0.99
- Self-Realization	Low High	31 968	17.91 (2.52) 19.09 (1.97)	t(31.9)=-2.61, p=0.01	-1.19

Table 24: T-tests for High and Low'Kiwi' ACE-R Scorers (<82>) on mean quality of life scores

#### DISUSSION

The aim of this study was to investigate the association between cognitive functioning and quality of life within a sample of community dwelling older adults.

Results showed that as ACE-R score increased, ratings of perceived health (SF-PCS), WHOQOL and CASP significantly increased, suggesting that better ACE-R score is associated with a higher quality of life on those measures. 'Kiwi' ACE-R score was more strongly associated with perceptions of physical health than mental health in older adults.

The strongest associations in this study were between perceived physical health and the 'Kiwi' ACE-R sub-domains: Fluency and Visual-spatial. These cognitive domains both rely heavily on executive functioning skills, visual and motor abilities, which may be reduced in those with poor perceived physical quality of life. A few studies have looked specifically at the association between perceived physical health and cognitive domains and found associations with cognitive

<sup>&</sup>lt;sup>7</sup> N's are uneven across quality of life measures due to missing data

set-shifting, working memory (Davis, Marra, Najafzadeh, & Liu-Ambrose, 2010), processing resources (Hultsch et al., 1992) and perceptual speed (Earles, Connor, Smith, & Park, 1997). These authors suggest a number of hypotheses that explain the association; particularly that, executive function tasks such as planning, sequencing and monitoring goal directed behaviour are essential for medication management, dietary and lifestyle changes; all factors that are associated with health. Furthermore, health-related quality of life is associated with the ability to perform instrumental activities of daily living which relies heavily on executive functioning skills. Earles et al., (1997) suggest that self-reported health mediates age differences in memory through perceptual speed. He argues that biological functions such as health influence first tier cognitive abilities, (such as information processing speed) which can then influence higher order processes such as executive functioning. Unfortunately information processing was not measured in the current study and the links between self-perceived physical health and verbal fluency and visual-spatial cognitive domains can only be hypothesized.

While there were significant associations between quality of life measures and 'Kiwi' ACE-R score, the actual effect was quite low 1-5%. A number of other studies have also found this; with other factors having a stronger association than cognition (Banerjee et al., 2006; Jones et al., 2003; Thorgrimsen et al., 2003). The unique contribution of 'Kiwi' ACE-R score to quality of life while controlling for the known correlates was minimal and non-significant. Consistent with Lawton's (Lawton & Powell, 1991) conceptualization with quality of life, other variables entered into the current study regression model explained a significant amount of the variance in quality of life scores (ranging from 36%-66%). Similar to other studies of older adults, (Bowling et al., 2002; Netuveli & Blane, 2008; Wiggins, Higgs, Hyde, & Blane, 2004) common themes emerge for older adults for maintaining higher ratings of quality of life in the domains of social, physical, emotional and economic. That is, feeling socially supported and worthy, having satisfaction with an improved quality of life for all quality of life scales. The results confirm that quality of life is not reducible to any single factor, instead many things contribute to quality of life ratings.

Those who showed cognitive functioning impairment ('Kiwi' ACE-R score <82) scored significantly lower on all quality of life measures, particularly on the CASP and its subdomain of Autonomy & control. Those who had poorer cognitive functioning were less satisfied with their: overall quality of life, physical health, general health, ability to perform activities of daily living, and with personal relationships (items from WHOQOL-8). They also felt they did not have enough energy or money, less satisfied with their social functioning and were limited in function by emotional problems (items from SF-12). They also tended to believe that their age was a barrier to doing things and that what happened was out of their control (CASP items). However, these people scored more highly on CASP items relating to optimism (life has meaning and opportunities), energy and enjoyment of life. Given that the low cognitive functioning group was small these results must be viewed with caution.

This result was contrary to past research which has found that cognitive impairments do not generally impact ratings of quality of life, potentially due to resilience and adaptation to cognitive difficulties. (Logsdon et al., 2002b; Ready et al., 2004; Thorgrimsen et al., 2003). However, this result is similar to that obtained by Llewelyn et al., (2008b) who found low scores on the CASP related to low scores on cognitive functioning. Jones et al., (2003) suggests that people with good cognitive functioning are better able to appreciate the subtle positive aspects of living and adapt in a manner that enhances wellbeing. However, in this study low 'Kiwi' ACE-R scorers showed more optimism and gave greater meaning to life than high scorers. But, their perceptions about the limitations of physical health and their feelings of having a lack of control and autonomy may have superceded their optimism. It is also possible that New Zealanders differ to people from other countries in their ability to show resilience and adapt to the demands faced through cognitive functioning difficulties. This would need to be investigated through more specific questions relating to coping strategies. It is also possible that participants scoring low on the 'Kiwi' ACE-R did not understand the quality of life measures or had poor insight into their quality of life; however, generally research does not support this contention (Logsdon et al.,

2002b). Furthermore, cognitive functioning may have impacted on physical functioning, which was strongly linked in this sub-sample.

There was no relationship between 'Kiwi' ACE-R score and self-perceived mental health (SF-MCS). Veenhoven (2000) argues that overall life-satisfaction is mostly inferred from affective experience and that cognitive appraisals are often instigated by affective cues. Therefore it could be argued that those who may be depressed are more likely to cognitively appraise their situation in a more biased way (i.e., an affective fallacy). However, this contention was not supported in this study with no relationship between the two factors. No known studies have looked specifically at SF-MCS and cognitive functioning previously. Given that the SF-MCS is a measure of subjective mental health and is often cited as a valid measure of mental health (for both depression and anxiety symptoms) in epidemiological research (Gill, Butterworth, Rodgers, & Mackinnon, 2007) it would be expected to be associated with cognitive functioning as a number of studies show associations between cognitive functioning and depression (La Rue et al., 1995; Paterniti, Verdier-Taillefer, Dufouil, & Alperovitch, 2002b; van den Kommer et al., 2012). Furthermore, cognitive functioning can be influenced by a person's mood state through declines in information processing (Comijs, 2001), poorer processing speed, shifting attention and inhibition (Beaudreau & O'Hara, 2009). Eysenck et al., (2007), suggested that preoccupation with threat information (caused by anxiety) coupled with age-associated reductions in cognitive processing could potentially lead to reductions in attention and other executive functions, such as inhibition, in mildly anxious, normal older adults.

Comparisons of those who are classified as having clinical signs of anxiety or depression could be compared to those who have an absence of these symptoms, and then compare their ratings of subjective mental health. This may help to highlight why in this sample there was no association. It is possible that psychological and cognitive factors, are independent of perceived quality of life, due to the protective effects of other factors of quality of life such as social and physical factors. A study on psychological well-being (one aspect of quality of life) found that it was independent from the absence of psychological distress or pathology (Huppert & Whittington, 2003). It was hypothesized that psychological well-being may reduce stress by enhancing psychological resources, and increase neural efficiency. Therefore, even if someone shows symptoms of depression and anxiety, if they are well supported and perceive their wellbeing as high, it may have a protective function for cognitive functioning difficulties.

## Strengths

No known studies of similar nature to this one, comment on the individual cognitive domains and their association with quality of life. Most of the studies presented in the literature review have used measures which are too brief to denote different cognitive domains (e.g. Mini Mental Status Examination or Telephone Interview of Cognitive Status). By using a more robust and comprehensive cognitive screening measure this study has been able to show which domains are more significantly associated with quality of life outcomes and therefore interventions that improve upon specific cognitive areas can be targeted.

This is the first known study to investigate the unique contribution of cognitive functioning to quality of life, independent of known correlates. The majority of studies looking at cognitive functioning and quality of life only control or socio-demographic factors such as age, sex and education (Konagaya et al., 2009; Llewellyn et al., 2008b; Logsdon et al., 2002b; Teng et al., 2012); many neglecting to control for other factors known to influence quality of life and cognitive functioning such as physical, psychological and social domains. This study has identified the unique contribution cognitive functioning has in explaining the variance in quality of life while controlling for those correlates.

# Limitations

The ACE-R does not measure information processing speed. This is one of the first cognitive domains to show age-related effects. This limits the potential to find the unique contribution of

this domain for explaining variance in quality of life and reduces the ability to identify participants who may be declining in cognitive function earlier in life.

Due to the cross-sectional nature of this research it was not possible to determine the direction of causation amongst the relationships found. The direction of influence and even the type of influence between cognition and quality of life is unclear. Research has shown that having a high quality of life may reduce stress by enhancing psychological resources and increase neural efficiency, and that inducing positive mood states influences cognitive performance over short periods (Isen, 2002) and potentially longer periods of time (Llewellyn et al., 2008a). Conversely, as quality of life decreases, cognitive functioning may also decline due to its influential effects, (e.g., social support, or health declines which could impact cognition) (Jones et al., 2008). On the other hand, deteriorating levels of cognitive functioning may lead to reduced levels of quality of life through the deficits of memory, attention, judgement, insight, and communication which affect an individual's ability to enjoy life like they once had and add stress, reduce independence and ability to carry out activities of daily living, participation in leisure activities and create isolation (Ahlsio et al., 1984a). From a more positive view, intact cognitive functioning may promote increased quality of life through promotion of independence and interaction with society (Gabriel & Bowling, 2004) which are known protective factors for maintaining cognitive health. These potential directions of influence can be investigated in longitudinal research.

# Future Research

This research sets up a baseline from which the above hypotheses can be investigated through longitudinal study design. Longitudinal studies provide information that cross-sectional studies can not, such as estimates of individual rates of decline, risk factors for decline and data on correlations between changes in cognitive ability and changes in other non-cognitive domains. Furthermore, the influence of age versus cohort effects can be seen more clearly through longitudinal research (Blane et al., 2004). Behaviours and skills that are actively declining in the cognitively impaired group may be having an influence on perceptions of quality of life and may

change depending on what stage their cognitive dysfunction is at. Therefore, it is important that this is adjusted for when measuring quality of life ratings, which can be done in longitudinal work.

#### Conclusion

The results presented show that cognitive functioning and quality of life have a significant association, particularly in those who are experiencing cognitive functioning difficulties. This highlights the importance of ensuring interventions target these domains so that quality of life can improve, particularly in the areas that have the most meaning for older adults (in particular perceived physical health). Policies and primary health care services should be advocating the maintenance of a healthy lifestyle, particularly the enhancement of perceived physical quality of life so that a quality life can be maintained despite increasing cognitive difficulties.

#### Competing interests: None

#### **CHAPTER SIX: DISCUSSION**

The current thesis involved three studies – the first, a pilot study, which informed the second; the generation of valid norms of cognitive functioning in older adults using the ACE-R. The third applied this information by looking at the relationship between cognitive functioning and quality of life.

New Zealand, like other Western nations, is developing an ageing population. With this demographic shift there has been a push to enhance the quality of life of older adults by increasing wrap around services, better monitoring in primary care, and ageing in the home rather that in residential care. One of the largest contributors to needing residential care is the loss of independence and ability to perform activities of daily living, of which declines in cognitive functioning is the leading cause.

Cognitive functioning provides the basis of what we attend to, how well we attend,, what we choose to remember and how this information is expressed. It is a strong predictor of mortality (Schupf et al., 2005). Therefore, it is no surprise that declining cognitive functioning is a fear that many older adults have. There are a number of theories that provide a basis for understanding that what, when and how of cognitive change. Neuro-pathological theories explain the how, the continuum approach explains the when and the processing speed and effortful recall theories explain the what of cognitive change (e.g., the cognitive domains). The factors that mediate the processes alluded to in the theories are multiple and varied and include environmental (e.g., financial security), social (e.g., social support) and psychological factors (e.g., depressive symptoms) that can increase or decrease the impact of ageing on the brain. These are the factors that can give an idea of who may be at an increased risk of developing cognitive functioning difficulties.

With the increased shift in providing earlier assessment and intervention, there is a need for accurate measures that can identify people at risk. With earlier identification of those at risk it is possible to allay fears, provide interventions, educate the public and increase awareness about 'normal' cognitive ageing, delay institutionalization and reduce costs.

Most of the measures used in New Zealand have norms based on samples from the United Kingdom or the United States of America. There are very few studies that provide norms using New Zealand populations, and those that do use small sample sizes, inappropriate samples (e.g., university students) or do not provide norms across important demographic variables such as education and ethnicity. Using norms from other countries neglects the unique cultural differences that being in New Zealand may give. For example, just by virtue of residing in another country we are subject to different policies, education, nuances in language and even climate (e.g., vitamin D levels) which may all play a role in influencing cognitive function. This is demonstrated by studies in which New Zealanders were classified as cognitively impaired compared to overseas norms, simply by being unfamiliar with certain words or objects that are common overseas (Barker-Collo, 2001; Barker-Collo et al., 2002). Even within New Zealand there is known variation in how different ethnicities perform on cognitive functioning measures. Validity can be compromised when this is not taken into account (Lezak et al., 2004; Rosselli & Ardila, 2003).

There was a gap in the New Zealand research about cognitive functioning amongst older people living in the community. The lack of appropriate measures that are understandable and valid in this population has meant that accuracy in diagnosis of impairment has been lacking. Furthermore, the impact of demographic factors in influencing cognitive functioning had not been investigated in New Zealand samples.

Integrating cognitive functioning measures into longitudinal research can aid in the estimation of individual rates of decline, risk factors for decline and correlations between cognitive ability and other factors of life such as quality of life. The cognitive measures used in longitudinal studies,

assessed in the literature review used outdated and inadequate measures of cognitive functioning which reduces the ability to make valid conclusions. A review of measures found that the ACE-Rshowed promise as a screening tool for cognitive functioning in older adults.

The results of study one validated the use of the modified 'Kiwi' ACE-R for use with community dwelling older adults in New Zealand. The pilot sample did not differ significantly from the original control sample in the United Kingdom on scores obtained on the 'Kiwi' ACE-R and the adaptations to make it more relevant to our country (e.g., linguistic changes) appeared to make no difference to the overall validity of the measure. There was a good spread of scores with none of the participants attaining 100% and no extremely low scoring participants. On individual items there were some ceiling effects which limits the ability to show cognitive improvement in repeat testing. The alpha was slightly low, possibly due to the participants in this sample being healthy (i.e., non-dementing); the 'Kiwi' ACE-R items may not have discriminated well enough between different ability levels due to some items having zero variance which may have brought the alpha level down. The restriction of range in scores attenuates correlations. Participants enjoyed doing the test and did not struggle on any particular items. The 'Kiwi' ACE-R showed adequate concurrent validity. Differences in the answers for the naming sub-test suggested that a degree of flexibility was required in scoring the answers. No demographic factors (age, education, sex) or mood (depression or anxiety symptoms) had significant impact on ACE-R scores.

The psychometric properties were deemed good enough to include the 'Kiwi' ACE-R in the New Zealand Longitudinal Study of Ageing. Results from the first wave of this study were reported in article two. Results showed the 'Kiwi' ACE-R to have acceptable internal consistency and concurrent validity. In this sample (N=1005), scores on the 'Kiwi' ACE-R were significantly affected by age group, education, gender and ethnicity. Results were consistent with other research investigating factors that affect cognitive functioning. Being older or having a lower education was associated with lower 'Kiwi' ACE-R scores. Females scored higher than males, more so in the domains of language and fluency. Participants of New Zealand European ethnicity

scored significantly higher than participants from Māori ethnicity. The differences between these groups were irrespective of education level and age, suggestive that there are true differences amongst these ethnicities in how they score on the test. The reasons for this need to be explored in more detail; but it is possible that New Zealand Europeans feel more comfortable and familiar with this form of assessment or that it reflects a wider issue about social and structural inequalities within New Zealand which impacts on significant risk factors for cognitive functioning. Together these demographic variables, (age, education, ethnicity and sex) explained 19.8% of the overall variance in 'Kiwi' ACE-R score and it prompted demographic stratified norms. The rate of cognitive impairment was around 4.2%, similar to other countries' estimates of cognitive impairment in the community (Herzog & Wallace, 1997; Melzer et al., 1997). This rate increased by age group from 3% for under 55 years of age and up to 6% for those over 75 years of age. People who were male, had fewer qualifications and were older were more likely to show cognitive impairment. This study is the first known study to provide nationally representative norms for the assessment of cognitive functioning among a wide range of age groups and education levels as well as ethnic groups in New Zealand.

Study three applied this data in examining the relationship between cognitive functioning and quality of life. The literature review showed that quality of life quality of life is a complex, multidomain construct which changes with age. This meant that measures which would be specific to older people and cover the breadth of factors associated with ratings one's quality of life were required in the study. The factors that are known to influence cognitive functioning, (e.g., age, education, activity, social supports, physical health and emotional health) are also all factors that are known predictors of quality of life. Therefore the two concepts have a conceptual and overlapping association. However the direction and strength of the relationship and role of these variables is unclear and longitudinal research can help answer these questions. The literature suggested that cognitive functioning did not impact one's ability to accurately assess quality of life, nor ability to communicate this in tests. It also showed that in community studies there is often a relationship between cognitive functioning and quality of life, but it is mediated by a number of socio-demographic, environmental, physical and psychological factors (Bowling et al., 2002; Bowling et al., 2003; Farquhar, 1995).

The results of the current research found support for the link between cognitive functioning and quality of life, with a small positive correlation (ranging from 1-5% depending on how quality of life was measured). However, when controlling for other factors cognitive functioning became non-significant. 'Kiwi' ACE-R scores were most significantly associated with one's perceptions of physical functioning, with poorer 'Kiwi' ACE-R scores being associated with poorer perception of physical functioning. The relationship was stronger for those who scored low on the 'Kiwi' ACE-R, particularly their perceived physical functioning. It is possible that people with lower cognitive functioning are less able to adapt effectively to their physical difficulties or it is possible that having more physical problems leads to lower cognitive functioning due to possible reduced social interaction or other health needs that are associated with cognitive functioning.

# **Overarching Implications**

To date, most test norms developed for New Zealand samples are small in number, (e.g., less than 50 people in a sample) or use inappropriate samples to create norms (e.g., university students). This sample is large and representative which immediately provides benefits for use in clinical practice. The data presented in this thesis is most useful to clinicians who are screening for cognitive impairment in older people. It gives detailed normative information so that comparisons of the person being assessed can be accurately compared against a closely matched sample population. For example, having specific norms for Māori will help more accurate assessment and reduce the chances of misdiagnosis. This will aid in more accurate and valid conclusions about someone's cognitive functioning. Already this data has been requested by a number of clinicians working with older adults who realize the importance of using valid data which is unique to our specific population.

Results suggest that improving cognitive functioning in those that show impairments may improve quality of life, particularly in physical health areas. There are other factors show explain more of the variance in quality of life, such as feeling financially secure, having better physical health and mental health and in particular feeling socially included. This provides direction for interventions. For example, it may be beneficial to create more community related social support systems for older adults. This in turn may help to improve cognitive functioning (as social support is a known influencing factor for cognitive functioning).

The New Zealand government is promoting policies such as, ageing within your own home, increased independence and better wrap around care in primary services. Therefore the needs of the community need to be addressed within these policies and programmes. For example, systems of support should be expanded to not just those that show clear cognitive impairments, but also to include the early assessment of older people and to provide access to supports for other known contributors to both cognitive functioning and quality of life (e.g., better standards of living and improved social supports).

Additional training is needed for health professionals to detect cognitive impairment in its early stages. The ACE-R is already widely used within New Zealand District Health Boards but it is unclear if it is being used appropriately, (e.g., as part of a more comprehensive assessment). The ACE-R is a screening tool and as such can not be used as a diagnostic tool. The results and implications of ACE-R scores need to be understood and applied (including using the valid norms) consistently and correctly. This is why it is important to identify people who are showing signs of cognitive impairment to ensure that they are evaluated accurately by a health care professional and receive the appropriate care or treatment.

## **Future research**

This research provides a baseline of cognitive functioning in older adults and the association with quality of life; a stepping stone for future research. The integration of the 'Kiwi' ACE-R into the

longitudinal study means that answers to a number of questions raised in this thesis, particularly those about monitoring change can be examined in detail. For example, are the cognitive functioning changes noted with increasing age a cohort effect? What are the predictors or associated factors of change in cognitive functioning? What are the consequences of changes in cognitive functioning in terms of older persons' contributions to society, their adjustment and their need for care? What is the direction of causation between quality of life and cognition? Longitudinal studies can produce valuable answers to these questions. (Schaie & Hofer, 2001). This research is also the first of its kind in New Zealand to show differences between ethnic groups at older ages. These differences need to be explored more to see how cognitive tests can be modified, or how scores can be adjusted to be more appropriate to the person being assessed.

The ACE-R has now been modified due to the copyright laws of the MMSE which required the removal of the MMSE items from the ACE-R. The ACE-III has recently been developed and is being assessed for equivalency to the ACE-R with favourable results (Hsieh et al., 2013). A similar equivalency study is also required for the "Kiwi' ACE-III which is currently being developed.

Accurate estimates of cognitive impairment can be improved by comparing this non-clinical community sample with a clinical comparison group; using the same 'Kiwi' ACE-R measure. This will create precise predictive values and more sensitive and specific cut off scores, unique to a New Zealand population. The large variability in options for cut-off scores suggests that more research is needed to identify and validate an appropriate cut-off score, using the best definitions available.

# APPENDICES

## **Appendix A: Advertisement for volunteers**

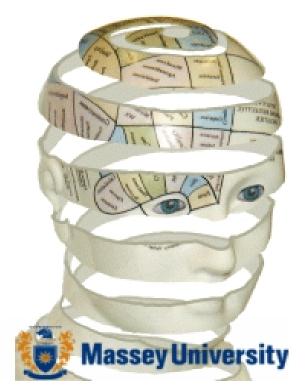
# **Recruitment Poster**

Massey University researchers are looking for adults to participate in a study looking at memory and attention abilities

If you are;

- Interested in learning about your cognitive abilities
- Aged over 55
- Living in the community

We would like to invite you to participate in our study. This study will take around 60 minutes of your time.



If you are interested in participating or want to learn more about this study, please contact;

Lauren Callow Massey University PhD student

lauren.callow@gmail.com

Thank you for your interest

Lauren Callow lauren.callow@gmail.com

. . .

# Recruitment email

To whom it may concern,

I am a doctoral student in Clinical Psychology at Massey University (Wellington) conducting a research study about the effects of ageing and mood on cognitive abilities like memory and attention. The study is intended to evaluate the effectiveness of a modified New Zealand cognitive measure for assessing any cognitive problems that older people may have and the effect (if any) that mood may play with cognitive abilities. This study is interested in people who live in the community and are aged over 55.

I would like to invite you to participate in this study. Participation would involve a face to face meeting and completing some assessments which can take up to 60 minutes. Your participation will help us to understand and investigate further about cognitive abilities in older life and how mood may impact on these abilities.

Participation in this research is voluntary. Participants' answers will be completely confidential. The research will discuss group results and thus your identity will not be revealed in any publications (thesis, conference proceedings, and journals). Both printed and electronic data will be kept securely and only available to the principal researcher.

By participating in this research you will have the chance to learn about your own abilities compared to others your age and help form an idea of how well this cognitive measure is at measuring New Zealand adults. Participants will also be given a small koha (gift) for your time.

If you have any questions regarding this study or wish to participate and read the information sheet, do not hesitate to contact me through the email address: <u>lauren.callow@gmail.com</u> or leave a message on this 0800 number (TBA).

Please feel free to forward this email to other friends who might be interested.

Thank you for your time and support.

Kind regards,

Lauren Callow DClinPsyc Candidate Department of Health and Social Sciences Massey University (Wellington)

Ethics Approval

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 10/23. If you have any concerns about the conduct of this research, please contact Dr Karl Pajo, Chair Massey University Human Ethics Committee: Southern B, Telephone: 04 801 5799 x 6929, email humanethicsouthb@massey.ac.nz

## Letter to Agencies (an example)

Lauren Callow 57c John Sims Drive Broadmeadows Wellington, 6035 04-4616195 Lauren.callow@gmail.com

6 November 2013

Age Concern Wellington Branch Suite 4, Anvil House, Level 1 138-140 Wakefield Street, Wellington

Dear Age Concern Wellington,

My name is Lauren Callow. I am a University student at Massey (Wellington) studying towards a doctorate in clinical psychology. I am currently beginning a doctoral thesis looking at the appropriateness of a screening measure of cognition with older people. Within this topic is an interest in what cognitive changes may occur during the ageing process and if a person's mood has an impact on this.

I am looking to recruit a sample of 100 community dwelling New Zealand citizens who are aged over 55 years.

Is your organization able to assist me in any way in recruiting volunteers for this study? Currently I am looking at putting up flyers in appropriate places and giving short speeches to different organizations such as yours and accessing email lists of current members.

If you are able to help me in any way, or have some suggestions regarding how to recruit people please contact me either through this email, or by phone; 0274284100, 04-4616195. I have attached the information sheet that outlines the study which will be given out to anyone willing to participate in this research.

Kind regards,

Lauren Callow

# Appendix B: Information Sheet Memory and Attention in Older Adults

# About Me

Hello. My name is Lauren Callow and I am a Massey University student undertaking a research study for the qualification of a Doctorate in Clinical Psychology (DClinPsyc). I am undertaking this study to evaluate the appropriateness of a measure of cognitive function with older people. I am also interested in seeing what areas of cognition are affected by ageing and if mood has an impact on these abilities.

# About the Study

You are invited to participate in this *pilot* study looking at aspects such as memory and attention and how they change as you get older and *whether these abilities are affected by your mood*. Your participation will help form a picture of how *cognitive* abilities change as we age and will give you an idea of how you compare to others of your age.

## What it involves

The current study will involve asking a sample of 100 people, aged 55+ from the Wellington community to volunteer up to 60 minutes of their time to fill in some questionnaires asking basic demographic information, questions about your mood and looking at basic cognitive abilities such as memory, attention and perception. People who would like to participate in the study can contact me and we can arrange a time and place to meet. You will be offered a small koha (gift) to thank you for your time.

# **Risks, Support and Confidentiality**

I anticipate no discomfort or risk to you as a result of participation. If you do start to feel distressed you are more than welcome to discontinue the study at any time or decide not to answer some questions. Additionally, you are welcome to bring a long a support person with you if it will make you feel more comfortable. There will be no identifying information on any of the answer sheets and your confidentiality agreements will be stored separately from your results in a locked room at the Massey University campus in Wellington. Your results from the questionnaire will be entered immediately onto the computer and any answer sheets will be destroyed.

#### **Results**

You are welcome to an individual summary of your results and the overall results of the research once this study is finished. If you would like a copy sent to you or told to you over the phone please note your address and phone number down on the consent form provided. In addition, a summary of the project findings will be available online at <u>http://NZLSA.massey.ac.New Zealand /study-info.htm</u>

If your results suggest any serious difficulties or show that you or others are at any risk then the results may be discussed privately with my co-supervisor (Professor Janet Leathem, a highly experienced clinical psychologist who specializes in older adults). From this discussion we will be able to offer you options for support for any cognitive or mood difficulties you may be having.

# **Your Rights**

You are under no obligation to accept this invitation. If you do decide to participate, you have the right to:

- •decline to answer any particular question;
- •withdraw from the study at any time during the process;
- •ask any questions about the study at any time during participation;
- •provide information on the understanding that your name will not be used unless you give permission to the researcher;
- •be given access to a summary of the project findings when it is concluded

# **Contact Details**

You can contact myself or my main supervisor at any time with any issues regarding this study.

Student Researcher Name: Lauren Callow Phone: 0800 (TBA) Email: <u>lauren.callow@gmail.com</u>

Supervisor Name: Associate Professor Fiona Alpass Phone: (06) 356-9099 ext. 2071

*Co-Supervisor* Name: Professor Janet Leathem Phone: 801 5799, Ext 62035

# **Ethics Approval**

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application 10/23. If you have any concerns about the conduct of this research, please contact Dr Karl Pajo, Chair Massey University Human Ethics Committee: Southern B telephone 04 801 5799 x 6929, email humanethicsouthb@massey.ac.nz.

# **Appendix C: Consent Forms**

# Memory and Attention in Older Adults

# Participant Consent Form and Researcher Confidentiality Agreement

I have read the information sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree to participate in this study under the conditions set out in the information	tion sheet.	
Signature:	Date:	

Full Name:

If you would like a copy of your personal results and those of the research please include either your address, phone number or email and state which option is best to contact you by.

Preferred mode of contact:

In person:	
By mail: Address:	
Phone:	
Email:	

# **Confidentiality Agreement**

I, the researcher of this study *Lauren May Callow* agree to keep confidential all information pertaining to this participant.

Signature: ..... Date: .....

Interpreter's consent form.

# Memory and Attention in Older Adults

# INTERPRETER'S CONFIDENTIALITY AGREEMENT

# **Appendix D: Demographic Questionnaire**

All information on this questionnaire will be kept confidential. Please do not write your name on this questionnaire so that you may remain anonymous. Thank-you.

Age (please specif	ý)	Gend	ler (Please tick of	ne) 🗆 Mal	le 🗆 Female	
Ethnicity □ New Zealand Eu □ Cook Island Māc □ Other- such as D	ori	□ Chinese	Indian	-		
Relationship StateSingleWidowedOther (please specified)	Married De-facto	$\Box$ Civil Unior	permanently separ	ated		
<ul> <li>No Qualification</li> <li>Secondary School</li> </ul>	Educational Level <ul> <li>No Qualifications</li> <li>Secondary School qualification (school certificate, university entrance)</li> <li>Post-secondary certificate or diploma</li> <li>University Degree</li> </ul>					
Household Compe Live alone Live with a partn Other(s)	er or de fact					
<b>In general do you</b> <ul> <li>Excellent</li> </ul>			□ Good	🗆 Fair 🗆 Poo	r	
<b>How would you ra</b> <ul> <li>Excellent</li> </ul>				□ Poor		
How would you ra			<b>pared to two yes</b>	ars ago?		

# Appendix E: Cognitive and Mood measures Addenbrooke's Cognitive Examination-Revised

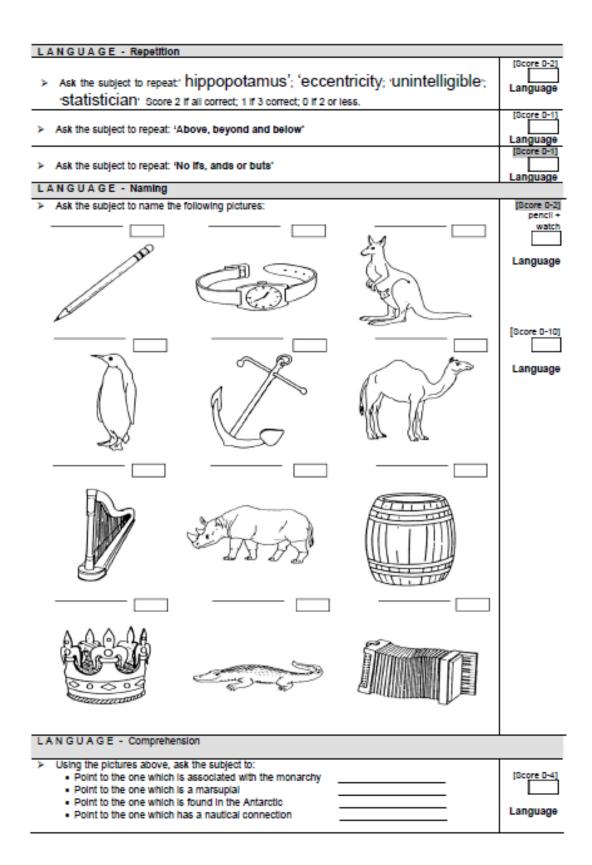
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ADDENB Revised	ROOKE Version	' <b>S</b> COG A (2004)	NIT - N	IVE E Z Adap	XAMIN tation 1f	ATION – A (December 20	CE-R 07)
Name : Date of birth : NHI number :	Date of birth : Tester's name:						
ORIENTATION		-					
> Ask: What is the	Day	Date	Mont	ħ	Year	Season	(Score 0-5)
> Ask: Which	Building/ Address	Floor/Ward	Town	n/Suburb	City	Country	(Score 0-5)
REGISTRATIO	N						
later'. Score only t Register number of tri	r subject repea the first trial (re als	ats, say ' Try to peat 3 times if	reme neces	mber thos	e you to repe e because l'r	at after me: lemon, n going to ask you	(Score 0-3)
ATTENTION &	CONCEN	TRATION					[Score 0-5]
Ask the subject: 'could you take seven away from a hundred?'. And then seven from each response (5 subtractions). If subject fails, ask: 'did you mean?' if subject still makes a mistake, switch to spelling. If subject corrects himself or herself, continue. Stop after five subtractions (93, 86, 79, 72, 65)					(for the best performed bask)		
Ask: 'could you pli	ease spell WO	RLD for me? 1	Then a	sk him/he	r to spell it ba	ackwards:	
	DL	RO	W				
MEMORY - Reca	11						
> Ask: "Which 3 obje	ects I asked yo	u to repeat an	d reme	ember?"			(Score 0-3)
MEMORY - Anter	rograde Memo	ory .					
Tell: ' I'm going to give you a name and address and I'd like you to repeat after me. We'll be doing that 3 times, so you have a chance to learn it because I'll be asking you later'					[Score 0 -7]		
Score only the third tri	al						
Harry Barnes 73 Church Street Woodville Hawkes Bay			1" - - -	Triai - 	2 <sup>nd</sup> Trial   -	3 <sup>rd</sup> Trial   -	
MEMORY-Retro	grade Memor	y					[Score 0 - 4 ]
<ul> <li>Name of current F</li> <li>Name of British R</li> <li>Name of the curre</li> <li>Name of the USA</li> </ul>	oyal family me int USA presid	ent					

VERBAL FLUENCY - Letter 'P' and animals		
Letters Say: 'I'm going to give you a letter of the alphabet and I'd like you to generate as many words as you can beginning with that letter, but not names of people or places. Are you ready? You've got a minute for that and the letter is letter P'	(Score	0 - 7]
	>17 14-17 11-13 8-10 6-7 4-5 3-4 <3 total	7 6 5 4 3 2 1 0 0
Animals Say: 'Now let's change. I'd like you to generate as many animals as possible, any kind of animal, beginning with any letter, it doesn't matter'.	(Score	0 - 7]
	>21 17-21 14-16 11-13 9-10 7-8 5-8 <5-8 <5 total	7 6 5 4 3 2 1 0 0
LANGUAGE - Comprehension		
> Show written instruction:	[Sco	re 0-1)

# **Close your eyes**

> 3 stage command: 'Take the paper in your left hand. Fold the paper in half. Put the paper on the floor'	[Score 0-3]
(use right hand if subject is left handed)	
Ask the subject to make up a sentence and write it in the space below:	(Score 0-1)
Score 1 if sentence contains a subject and a verb (see guide for examples)	



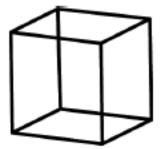
Ask the subject to read the following words:	[Score 0-1]
sew	
pint	
soot	
dough	
height	

> Overlapping pentagons: Ask the subject to copy this diagram:



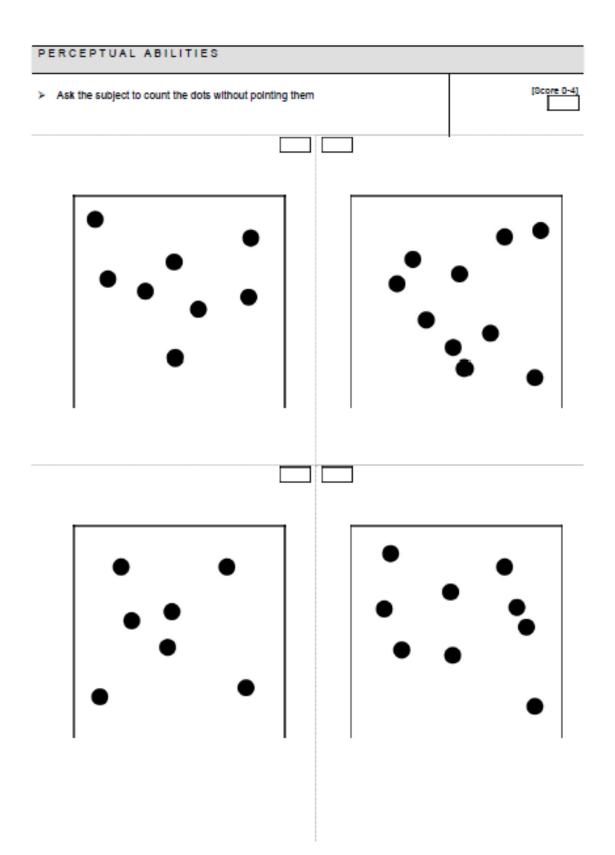


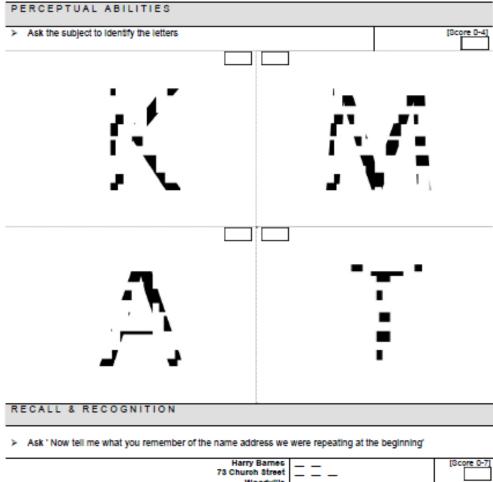
[8cg	re	0-2]
I		
	_	



> Clock: Ask the subject to draw a clock face with numbers and the hands at ten past five.

[Score 0-5]	





	-	73 Church Street		Locore of
		Woodville		
		Hawkee Bay	=	
will help to recall only			i and ask the question(s) ti es):	hat (Score O
Jerry Barnes	Harry Barnes		Harry Bradford	recalled
37	73		76	recalled
Church Road	Cathedral Street		Church Street	recalled
Norsewood	Woodville		Dargavile	recalled
Hawkes Bay	Hicks Bay		Bay of Plenty	recalled
General Scores				MSE /3
				CE-R /10
Fractionated scorir	ng			
Cut-off <88 gives 94% se	ensitivity and	Attention and Orientation		
	9% specificity for dementia Momory			
Cut-off <82 gives 84% se				ency /
00% specificity for demen	ntia		Lang	
100 ma 20 mm			Visuosp	patiai /

V1f (30-12-07)

The citation for the development and validation of this test is; Mathuranath, P., Nestor, P., Berrios, G., Rakowicz, W., Hodges, J. (2000) A brief cognitive test battery to differentiate Alzheimer's disease and frontotemporal dementia. *Neurology*, 55 (11), 1613-1620.

# Measures used in the Health Retirement Study (US)

# **Immediate Free Recall**

I am going to read a set of 10 words and ask you to recall as many as you can. We have purposefully made the list long so that it will be difficult for anyone to recall all the words- most people recall just a few. Please listen carefully as I read the set of words because I cannot repeat them. When I finish, I will ask you to recall aloud as many of the words as you can, in any order

List

- Hotel
- River
- Tree
- Skin
- Gold
- Market
- Paper
- Child
- King
- Book

Note: number correct, number wrong and number forgotten. 1 point for each correct answer

# Similarities

Please describe the way that these pairs of words are alike

- Orange and banana
- Dog and Lion
- Eye and Ear
- Egg and Seed
- Air and Water
- Fly and tree

Note: 2 points for each correct answer

*1 point for partially correct 0 points for incorrect or refused or d/k response* 

# Vocabulary (WAIS-R)

Please define these words the best you can

- Repair
- Fabric
- Domestic
- Remorse
- Plagiarize

Note: 2 points per correct answer

*1 point for partial answer 0 points for incorrect or refused to answer* 

# Numeracy

Next I would like to ask you some questions which assess how people use numbers in everyday life.

- If the chance of getting a disease is 10%, how many people out of 1,000 would be expected to get the disease?
- If 5 people all have the winning numbers in the lottery and the prize is 2 million dollars, how much will each of them get?
- Let's say you have \$200 in a savings account. The account earns ten percent interest per year. How much would you have in the account at the end of two years?

Note: 1 point for each correct response (100, \$400,000, 242)

# **Delayed Free Recall**

A little while ago, I read you a list of words and you repeated the ones you could remember. Please tell me any of the words that you remember now. (5min after initial recall)

*Note: number correct, number wrong and number forgotten. 1 point for each correct answer Note: Total recall score (delayed + immediate recall scores)* 

These cognitive questions are taken from the Health and Retirement Study (US) which is a combination of WAIS-R and TICS questions. Mary Beth Ofstedal, Gwenith G. Fisher and A. Regula Herzog. *Documentation of Cognitive Functioning Measures in the Health and Retirement Study*. HRS Documentation Report DR-006 (March 2005)

## **Geriatric Depression Scale (GDS)**

Choose the best answer for how you have felt over the past week:

- 1. Are you basically satisfied with your life? YES / NO
- 2. Have you dropped many of your activities and interests? YES / NO
- 3. Do you feel that your life is empty? YES / NO
- 4. Do you often get bored? YES / NO
- 5. Are you in good spirits most of the time? YES / NO
- 6. Are you afraid that something bad is going to happen to you? YES / NO
- 7. Do you feel happy most of the time? YES / NO
- 8. Do you often feel helpless? YES / NO
- 9. Do you prefer to stay at home, rather than going out and doing new things? YES / NO
- 10. Do you feel you have more problems with memory than most? YES / NO
- 11. Do you think it is wonderful to be alive now? YES / NO
- 12. Do you feel pretty worthless the way you are now? YES / NO
- 13. Do you feel full of energy? YES / NO
- 14. Do you feel that your situation is hopeless? YES / NO
- 15. Do you think that most people are better off than you are? YES / NO

Although differing sensitivities and specificities have been obtained across studies, for clinical purposes a score > 5 points is suggestive of depression and should warrant a follow-up interview. Scores > 10 are almost always depression.

- 0 4 normal, depending on age, education, complaints
- 5 8 mild
- 8 11 moderate
- 12 15 severe

Yesavage, J.A., Brink, T.L., Rose, T.L., Lum, O. Huang, V., Adey, M., Leirer, V.O. (1983). Development and Validation of a Geriatric Depression Screening Scale: A Preliminary Report. *Journal* of Psychiatric Research, 17, 37-49.

# Center for Epidemiologic Studies Depression Scale

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the <u>past week</u>.

(Tick ONE circle on each line)	Rarely or none of the time	Some or a little of the time	Occasiona lly or a moderate amount of time	All of the time
I was bothered by things that usually don't bother me		2	3	4
I had trouble keeping my mind on what I was doing	(1)	(2)	(3)	4
I felt depressed		(2)	3	4
I felt that everything I did was an effort	(1)	(2)		$\overbrace{4}$
I felt hopeful about the future	$\widetilde{\mathbf{O}}$			
I felt fearful				
My sleep was restless				X
I was happy				
I felt lonely		(2)		
I could not "get going"		$\begin{pmatrix} 2 \\ 2 \end{pmatrix}$	(3)	4

(CES-D scale Radloff, 1977)

# **Geriatric Anxiety Inventory**

Please answer the items according to how you've felt in the last week. Tick the circle under AGREE if you mostly agree that the item describes you; tick the circle under DISAGREE if you mostly disagree that the item describes you.

		AGREE	DISAGREE
1	I worry a lot of the time.	0	0
2	I find it difficult to make a decision.	0	0
3	I often feel jumpy.	0	0
4	I find it hard to relax.	0	0
5	I often cannot enjoy things because of my worries.	0	0
6	Little things bother me a lot.	0	0
7	I often feel like I have butterflies in my stomach.	0	0
8	I think of myself as a worrier.	0	0
9	I can't help worrying about even trivial things.	0	0
10	I often feel nervous.	0	0
11	My own thoughts often make me anxious.	0	0
12	I get an upset stomach due to my worrying.	0	0
14	I always anticipate the worst will happen.	0	0
15	I often feel shaky inside.	0	0
16	I think that my worries interfere with my life.	0	0
17	My worries often overwhelm me.	0	0
18	I sometimes feel a great knot in my stomach.	0	0
19	I miss out on things because I worry too much.	0	0
20	I often feel upset.	0	О

Pachana, N.A., Byrne, G.J., Siddle, H., Koloski, N., Harley. E., & Arnold, E. (2007). Development and validation of the Geriatric Anxiety Inventory. *International Psychogeriatrics*, *19*, 103-114.

#### **Appendix F: Scales used in Article three**

# Social Provisions Scale (Cutrona, 1984)

The SPS was developed to examine the degree to which respondent's social relationships provide various dimensions of support. The six provisions include guidance (advice or information), reliable alliance (assurance that others can be counted on in times of stress, reassurance of worth (recognition of one's competence), attachment (emotional closeness) social integration (a sense of belonging to a group of friends), and opportunity for nurturance (providing assistance to others). Scores are made on a 4 point scale for the extent to which each statement describes their current social network. Responses range from 1 (strongly disagree) to 4 (strongly agree). Scores are derived for the six provisions as well as a global social support score. Scores can predict adaptation to stress. It takes 5 minutes. Internal consistency is acceptable 0.70 and test–retest 0.37-0.66 (Cutrona, 1984). Correlates with measures of social networks and satisfaction with different types of social relationships among the elderly (Cutrona, 1984).

*Economic Living Standards Index (ELSI) (Jensen, Spittal, Chrichton, Sathiyandra, & Krishnan, 2002)* Is a survey tool for measuring people's economic standard of living. This refers to the material aspect of wellbeing that is reflected in a person's consumption and personal possessions (e.g., household durables, clothing, recreations, access to medical services). The ELSI tool yields a score from combining information from x items and it takes 4-6 minutes to complete. Scores are rated from severe hardship, significant hardship, some hardship, fairly comfortable, comfortable, good, very good. Profiles related to the extent people lacked basic items of consumption (e.g., didn't go to doctor because couldn't afford), extent to which people had comfort and luxuries (e.g., holidays), extent to which people had financial problems or problems with accommodation.

## Center for Epidemiologic Studies Depression Scale (CES-D 10). Radloff (1977),

The CESD is a self-report scale designed to screen for depressive symptoms in general populations, with an emphasis on depressed mood over the last week. Each item is rated on a four-point scale, scored from 0 to 3. An example of an item measuring depressive affect is "*I was bothered by things that don't usually bother me*". The psychometric properties of the CES-D 10 item are comparable with the original 20-item scale with reliability coefficients ranging from 0.85-0.91 and test re-test reliability studies show moderate correlations (r=0.51-0.67) (Irwin et al., 1999). Validity ratings between other depression measures (Symptom Checklist-90, Hamilton Rating scale for Depression and the Geriatric Depression Scale) range from 0.49-0.89 (Radloff & Locke, 2000). Using an optimal cut-off score of 4 the sensitivity of the 10-item CES-D was 100% and specificity, 93% (Irwin et al., 1999), when used with adults over 60 years of age. New Zealand studies suggest good internal consistency with mature older adults, ( $\alpha$ =0.88-0.92) (Brown et al., 2002) and middle aged women (Knight et al.,

1997). The CES-D has demonstrated suitability for older populations (Brown et al., 2002), including New Zealand and it has widespread use internationally, which both attests to its reliability and validity for a variety of subpopulations, and allows for greater comparability with existing research. The CES-D has been used in a number of large epidemiological studies including; the National Health and Nutrition Examination Survey (NHANES), the Established Populations for Epidemiologic Study of the Elderly (EPESE), the National Longitudinal Surveys (NLS Mature Women, NLS-Older Men, NLSY), and the Americans' Changing Lives study (ACL).

#### Geriatric Anxiety Inventory (GAI). (Pachana et al., 2007).

The self-report measure designed to assess common symptoms of anxiety in older adults, It contains 20 items with a dichotomous response format "agree/disagree". An example of an item is, "*I think of myself as a worrier*". In the original paper internal consistency was high,  $\alpha$ =0.91. Convergent validity with a number of other anxiety scales (e.g., the State Trait Anxiety Inventory and Beck Anxiety Inventory and the Positive and Negative Affect Schedule) ranged from 0.70-0.80 (Pachana et al., 2007). A New Zealand study of older adults (n=32, mean age = 75.5) found that a cut off of 8/9 (out of 20) has a sensitivity of 73% and a specificity of 80% in identifying people with an anxiety disorder. (Cheung, 2007).

#### Wenger Network Assessment Instrument (Wenger, 1991)

A measure that assesses the informal support networks of older adults. Five support networks are assessed based on the nature of the person's relationships with the support networks of: family dependent (focuses on nearby kin ties, close family relationships and peripheral friends and neighbours), locally integrated (close relationships with family, friends and neighbours), local self-contained (arms-length relationships or infrequent contact with at least one living relative in the same or adjacent community), wider community focused (active relationships with distant relatives, high salience of friends and few neighbours) and private restricted support network (absence of local kin other than a spouse, minimal contact with neighbours, no local friends and lack of wider community contact or involvement). These support networks are assessed through questions that assess how close people live to these support networks or how often you have contact with them (on a 1-5 scale). The scores are summed and a preferred network type assigned to the respondent.

The De Jong Gierveld short scales for emotional and social loneliness (De Jong Gierveld & Van Tilburg, 1999). This is an 11 item questionnaire. Examples of items are: "I experience a sense of emptiness around me" and "I can rely on my friends whenever I need them". The word loneliness has not been used in the items of the loneliness scale to avoid reactions of respondents who are aware of the stigma of loneliness. The scale has been used in several surveys and proves to be robust, reliable

and valid instrument. It is scored in a yes/no format with scores ranging from 0 (not lonely) to 11 (extremely lonely).

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