

People with Dementia in the Driving Seat: Using a Participatory Approach to Research in
the Development of a Driver Screening Tool.

Thesis submitted for the degree of

Professional Doctorate

The University of Salford

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Thesis Submission April 2015

Abstract

Entitlement to drive is now viewed by many people as an essential component in the maintenance of independence (Box et al, 2010). Private motor vehicles are considered a key component in many aspects of contemporary life and are particularly important for people with a limitation in personal mobility. The driving task involves the smooth integration and coordination of a number of cognitive, perceptual and physical elements (Hoffman and Snyder, 2005). Testing tools designed to evaluate the effect of cognitive impairment upon driving are available but many perform poorly when evaluating both older individuals and people with a diagnosis of dementia (Molnar et al, 2006).

This research project aimed to give voice to the experience of people with dementia, carers and health professionals in the construction of an effective and clinically useful prototype screening tool, specifically for use in predicting the safety of drivers with a diagnosis of dementia. A participatory action research approach was taken with two separate groups formed from a dementia volunteer support group and a health professional dementia special interest group. The key findings of the research identified characteristic driving behaviours associated with a decline in driving safety and these were used to develop a dementia and driving screening tool. Additionally, a comprehensive information guide for the monitoring and management of driving with dementia was constructed through the action of group meetings. The experiences of both research groups strongly suggested that early consideration and planning is essential in the successful management of driving and eventual driving cessation for people with dementia.

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Acknowledgments

Acknowledgments

A number of people have been important in enabling me to undertake the Professional Doctorate and complete this research project.

Firstly, I owe a great debt of gratitude to all the people who agreed to take part in the project. I am extremely thankful for their patience, trust and enthusiasm for the topic, without which the project could not have been undertaken. I would like to offer particular thanks to Barbara and the staff at the Bolton Dementia Support Group who were very supportive throughout and to the Janet, Carol and Denise from the Health Professionals who were extremely supportive from the beginning of the project.

Secondly, I would like to thank my supervisors Dr Jackie Taylor and Chris Smith, whose support, advice and time have been vital in completing the research and thesis. I would also like to thank them enormously for the leap of faith in encouraging and enabling me to pursue a participatory approach to the research and all the difficulties this involved. I am grateful to the University of Salford for making the Professional Doctorate course available and providing support throughout the course of the study.

Thirdly, I would like to thank from the bottom of my heart my family for having belief in my ability to complete the project when I did not. Special thanks are due to Emma, my wife and Will, my son, who have been patient and supportive when I have been unable to share family times. I would also like to thank my Mum and Dad who eagerly await the conclusion of the process.

Finally I would like to thank my colleagues in the field of driving assessment who have supported me for the duration of the studies, particularly Barbara Hatton who has encouraged and supported and helped make it financially possible for me to continue with the Professional Doctorate.

Abbreviations:

Abbreviations:

ACE – R	Addenbrook’s Cognitive Evaluation - Revised
AD	Alzheimer’s Disease
ADL	Activities of Daily Living
DfT	Department for Transport
DLB	Dementia with Lewy Bodies
DH	Department of Health
FTD	Frontotemporal Dementia
CDT	Clock Drawing Test
DADL	Domestic Activities of Daily Living
DVLA	Driver and Vehicle Licensing Agency
EU	European Union
IADL	Instrumental Activities of Daily Living
ICD	International Classification of Diseases
OT	Occupational Therapist
ONS	Office of National Statistics
PADL	Personal Activities of Daily Living
SIG	Health Professional Special Interest Group
TMT -A	Trail Making Test A
TMT-B	Trail Making Test B
RDB	Rookwood Driving Battery
VaD	Vascular Dementia
VSG	Volunteer Support Group
WHO	World Health Organisation

Chapter One: Introduction to the Thesis:

This thesis details a participatory action research study carried out with a dementia support group and a group of health professionals with an interest in dementia in the North West of England. The introduction presents an overview of the thesis, providing the background and a rationale for the project and for the approach chosen to conduct the research. It will also detail my own position as researcher and present a description of the structure of the thesis. The purpose of this study was to explore the experience of health professionals and people with a diagnosis of dementia and their carers and to use these experiences to form the basis of a prototype screening tool for use in identifying decrements in driving safety.

Driving as a Living Skill

Entitlement to drive is now viewed by many people as an integral component in the maintenance of independence (Lavery et al, 1996). Private motor vehicles are seen to be an essential tool in modern society (Corr and Bayer, 1995; Holmqvist et al, 1998). Vehicles offer a flexible, convenient and accessible means of overcoming barriers imposed by changes in societal structures, the environment and reductions in the individual's level of function (Lister, 1999). More recent changes in land use planning have encouraged out of town developments that have served to decentralise retail, leisure and even health amenities (Lucas, 2009). The benefits of personal motor vehicle transportation are clear for the wider population but are particularly apparent for people with a limitation in mobility. This, along with demographic changes, may explain why within the United Kingdom's population, older drivers continue to represent the fastest growing group of drivers (Box, 2010).

Reliance upon the motor vehicle may however compel individuals to continuing to drive when they are no longer safe to do so. The driving task involves the smooth integration

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and coordination of a number of cognitive, perceptual and physical elements that include sharing and focussing of attention, decision making, visuospatial interpretation and visuomotor integration (Hoffman and Snyder, 2005). It is these elements that are frequently affected by a range of conditions broadly termed as dementia. Addressing the concerns regarding driving is an enduring dilemma for many health professionals (Gillespie et al 1999; Hawley et al, 2010; Marshall and Gilbert, 1999). General screening tools designed to assist with this task are available but perform poorly with older drivers and for people with a diagnosis of dementia (Inwood, 2007; Molnar et al, 2006). Reasons for the reduced efficacy of the screening tools in this particular group of people are poorly understood but may be attributable to their focus and measurement of cognitive function without a clear understanding of its role in driving.

Frameworks for Determining Fitness to Drive

Approaches to licensing regulations for drivers differ internationally. In the United States licensing policy varies between states but most states require the individual to re-apply for their license at the age of between 65 and 70 years. During this process investigations of any medical conditions likely to impact driving safety are made (National Highway Traffic Safety Administration, 2005). European licensing processes vary from those providing lifelong licensing without subsequent medical checks to more stringent approaches requiring driving license renewal every 5 years from the age of 45 in Finland (Mitchell, 2008). In the United Kingdom ordinary driving licences are valid until the age of seventy and are renewed every three years thereafter. The Secretary of State for Transport, acting through the Medical Branch of the Driver and Vehicle Licensing Agency (DVLA) bears responsibility for ensuring that all licence holders are fit to drive (DVLA, 2011). The process of identifying when a driver may be unsafe relies upon the licensing authority

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receiving self-declaration from the licence holder or expert opinion from health professionals, police or relative (Adler, 1997). The medical enquiry process is illustrated below:

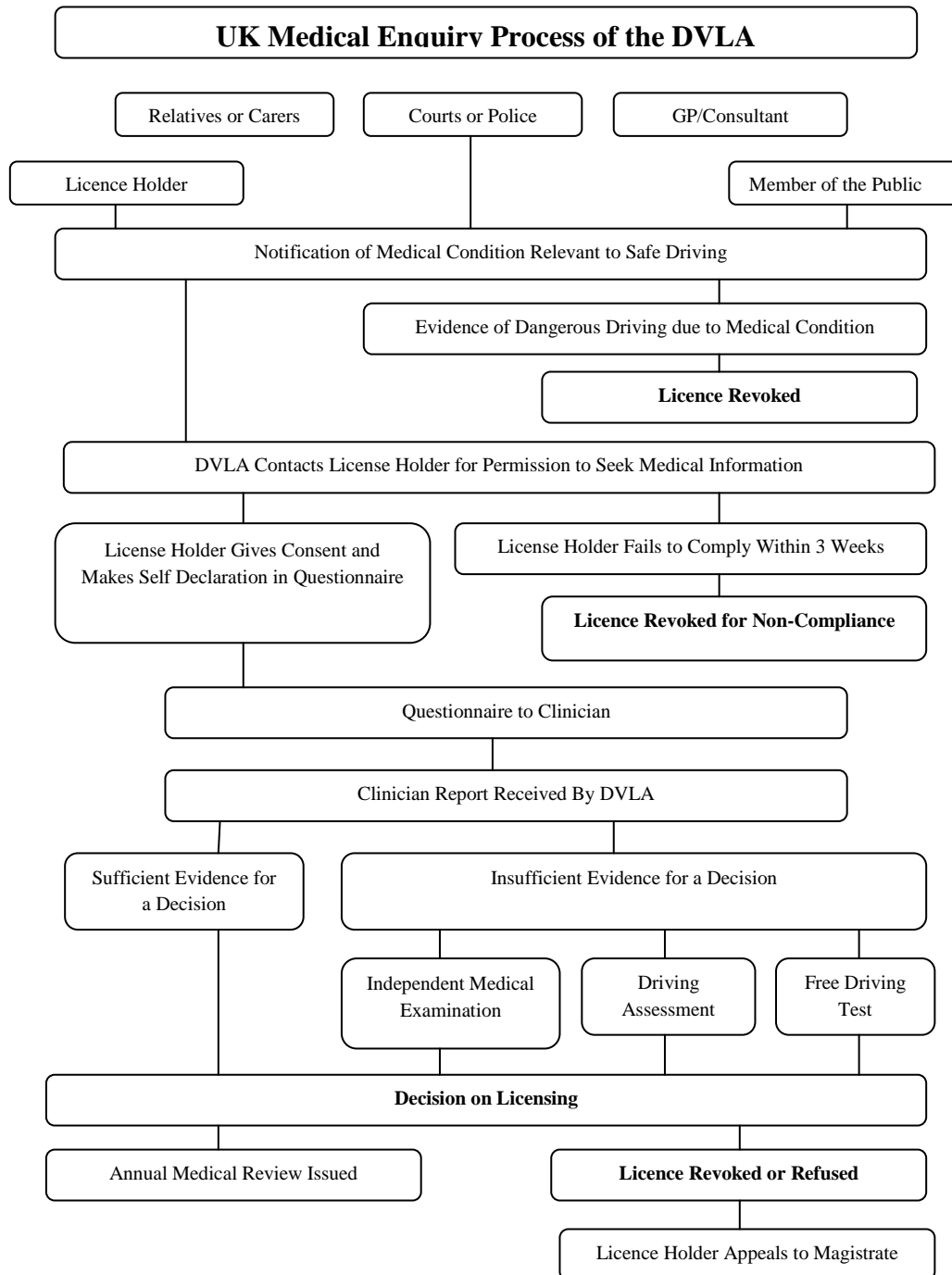


Figure 1

Adapted from British Psychological Society (2001)

The Rationale for the Research Project

Tools used in the screening for decrements in driving safety of people diagnosed with dementia within the UK are either generic screening tools or have been designed to test people with other medical conditions such as stroke and brain injury. All tools perform particularly poorly in their sensitivity and specificity in predicting the outcome of an on-road driving evaluation (Vrkljan et al, 2011). Rather than repeating approaches used in the development of previous screening, I considered that a change in the focus and the manner of development of the screening tool may generate data more sensitive to the task of driving and therefore increase the efficacy of such a screening tool. My aim was to invite health professionals and people with dementia to take an active role in the research process to provide a deeper exploration of the experiences of living and working with dementia and add clarity to the understanding of loss of functional skills in dementia.

Research Approach

The development of previous screening tools has centered upon the researcher's understanding of the driving task, nature of driving decrements and the manner in which clinical diagnoses manifest in driving performance. The resultant tools have a clinical and often, neuropsychological focus (British Psychological Society, 2001). It is evident that the topic of driving and driving safety has a significant clinical component, but I was eager to explore whether the engagement and active participation of individuals with personal experience of dementia might offer an alternative perspective regarding the progressive effect of dementia upon driving. I selected a participatory approach to the research project with the intention of engaging individuals with experience of the diagnosis of dementia. Two groups, with a differing relationship to the diagnosis of dementia, were contacted and these formed the basis of the two research groups. One group comprised health

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professionals working in the field of older age psychiatry with a specific interest in dementia care and the second group consisted of a combination of people with a diagnosis of dementia and carers of people with a diagnosis of dementia. The research process commenced with an exploratory phase comprising meetings which was then followed by cycles of reflection and action through which the features of the screening tool were developed. The two groups remained separate, but a degree of cross-pollination of ideas occurred between the groups, via my input, by means of a process of constant comparison. The participatory approach taken was intended to be democratic and empowering, encouraging members to share their experiences and stories, identify pertinent elements and play an active role in the planning and development of the prototype screening tool. The development phase of the screening tool included three meetings with each of the two groups. This was then followed by meetings in which the tool was finalised.

Thesis Structure

This thesis broadly follows a traditional thesis structure. The first two chapters are concerned with providing an introduction to driving and licensing in the UK, the human elements required for driving and the process of identifying when an individual's driving safety may be compromised by the onset of a medical condition. These chapters also explore the use of screening tools within this process. Chapter three details the research methods informing the approach adopted in the research and chapter four describes the project design. Chapters five and six present the findings of the research and incorporate a discussion of the findings. The decision to combine the research findings and discussion elements of the thesis was taken to facilitate detailed examination of the data and enable the reader to remain close to the development narrative. Chapter seven comprises an account of my reflexive journey that informed the development of the research, the

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screening tool and my own development as a researcher and practicing therapist. The final chapter examines key themes of the research not directly related to the development of the final tool. It also includes a methodological critique and details the recommendations resulting from the study.

Chapter Two: Literature Review: Dementia and Driving:

Chapter Introduction:

The purpose of this chapter is to present the key literature relating to driving with dementia. Initially it will examine the conceptual framework of dementia and will then explore the elements of the task of driving. The chapter also includes a discussion of current means of identifying decrements in driving as a consequence of dementia and incorporates a critical analysis of existing testing resources available to clinicians, both generic and specific to the driving task. It considers the impact of these factors upon legislative and medical approaches to dementia and driving. The chapter concludes with a description of a number of methodological difficulties specifically associated with research investigating the topic of driving and how these influence the efficacy of the evidence presented and subsequent driving testing tools.

2.1 Literature Search Strategy:

A search of the literature was carried out with the primary aims of delineating the research topic and an examination of the key areas of enquiry. It was also intended to provide methodological insights from previous studies and identify gaps in the existing body of research evidence. The literature search was carried out using web-based databases Cinahl, Embase, Medline, Cochrane Library, PsychInfo, Swetswise, Science Direct, OT Seeker and Elsevier auto. The key words used in the search were driving, drivers, older drivers, automobiles, vehicle, cars, dementia, mild cognitive impairment, frontotemporal dementia, vascular dementia, mixed dementia Alzheimer's disease, Lewy Body dementia, action research, participatory action research and community based participatory research.

Boolean operators were used to combine key words to widen and narrow searches.

International journal articles and unpublished literature, archived by the Forum of Mobility

Chapter Two: Literature Review: Dementia and Driving:

Centres, was accessed and a number of published and unpublished project reports obtained directly from the authors.

An exclusion of literature pre-dating a 10 year cut-off point was considered but not applied owing to much of the literature and subsequent screening tools prior to this being relevant in contemporary driving assessment practices. Literature obtained during the search was systematically evaluated using the Critical Appraisal Skills Programme (CASP) evaluation tool (Public Health Resources Unit, 2006). Additional evaluative questions were included that were pertinent to the particular study design (Crombie, 2004). Information generated during the evaluation of the literature was recorded in a literature synthesis table created using the Microsoft Excel worksheet. An example of this is contained in the appendix section (Appendix A). The review of literature has been structured using a thematic approach (Hart, 2006).

2.2 Elements of Driving:

For people familiar with driving a motor vehicle, the complexity of the task often goes unnoticed. The task of driving however requires a delicate integration and coordination of physical, cognitive and perceptual systems to enable safe driving. The smooth and coordinated operation of the vehicle controls need to be finely integrated with quickly changing events in the near and distant environment. The driver is required to attend to situations outside the vehicle, prioritising risks, and continually predicting and planning the development of situations (Lopez-Ramon et al, 2011). The driver must repeatedly evaluate information and respond accordingly. Reductions in performance or failures in this ability to observe, evaluate or respond can result in driving being unsafe.

Physical Components of Driving

The ability to operate the driver controls of the vehicle is critical for safe driving. Physical elements of driving focus upon muscular power and joint range of movement in operating the vehicle controls successfully. Requirements for steering and braking are specified by the European Driving Licence Directive (91/439/EC and 2006/126/EC) are measured functionally. The directive states that licences should not be issued to or renewed for applicants or drivers suffering from complaints or abnormalities of the locomotor system which make it dangerous to drive a power-driven vehicle. When steering, the driver should be able to maintain a straight line, change direction to the left and right both while moving forward and reversing, position the vehicle when parking and maintain a steady course when moving at speed. When braking, the driver should be able to apply graduated braking to achieve a smooth stop, maintain control of the steering when braking, react appropriately to dangerous situations and apply the parking brake from the driver's seat. Additionally, individuals should be able to apply a force of 500N and achieve a deceleration of 5.8ms^{-2} (European Union, 2006). Evaluation of these must be based upon a medical opinion or, where necessary, by practical testing.

A small number of studies have explored the relevance of discrete physical elements and their relationship to driving. A limitation in neck rotation has been a suggested determinant to a significant increase in crash risk however little supporting evidence exists for this (Marottoli et al, 1997). Similarly, limitations in range of movement of lower and upper limbs and of neck movement in older drivers are considered to be a contributory factor in older driver vehicle collisions (Koepsell et al, 1994; Meyer, 2004; Isler et al, 1997). A correlation between an increase in falls (Forrest et al, 1997) and difficulties in raising arms above shoulder level for female drivers (Hu et al, 1998) and vehicle collisions have been

Chapter Two: Literature Review: Dementia and Driving:

reported. While these studies provide credible data they are not supported with a greater body of research evidence.

The paucity of studies examining the impact of physical impairment and driving cessation may, in part, be due to the use of adaptive driving techniques and vehicle controls and poor measurement of impairment severity in relation to crash risk (Anstey et al, 2005). It is occasionally the case however that researchers unexpectedly reveal data that may indicate a relationship between physical impairment and decrements in driving. In a large scale study of drivers over the age of 65 in the USA, Stewart et al, (1993) examined 1,431 individuals who were involved in a wider research programme. Stewart's research project identified 142 individuals involved in road traffic crashes while taking part in the larger research project. Based on the results of the logistical regression, Stewart et al's study illustrated that age and gender were unrelated to an increase in crash risk. The results also indicated that medication and memory loss could not be linked to an increase in the likelihood of collision. The study did show that a sensory disturbance in the feet and lower limbs, an irregular heart beat and a high level of protein in the urine were important symptoms in an increased rate of driver crash involvement. The study also indicated a higher proportion of individuals with an upper or lower joint inflammation had an increased likelihood of being involved in a traffic incident. The results offered by this study should be treated with a degree of caution as although the primary study included a large number of participants the sub-study relating specifically to driving was much smaller (Stewart et al, 1993).

Cognitive and Perceptual Elements

The physical coordination of trunk and limb movements requires that many brain systems work efficiently and in harmony with each other. The act of driving a motor vehicle and interacting safely with other road users and obstacles requires the seamless integration of the body's sensory and cognitive systems. The judgment of the movement of an object that extends well beyond the boundaries of the human body and moves at speeds that exceeds its physical capacity is an extremely demanding task and, in evolutionary terms, a freshly developed skill (Rumar, 1990). Driving demands an exceptionally high level of cognitive output that occurs largely beyond the person's consciousness.

The primary cognitive components required for driving are not fully understood but agreement of the contribution of attention, memory, information processing, decision making and executive functioning exists (Apolinario et al, 2009; Meyer, 2004; Newby, 2015; Staplin et al, 1998). These components do not however operate in isolation but integrate the lower level motor and perceptual components with the higher level decision making processes.

One of the primary cognitive elements necessary for successful driving is that of attention. The mechanisms of attention clearly plays a significant role in the safe completion of the driving task but it's exact role has been difficult to locate with any certainty owing to the indistinct definition and lack of agreement upon a satisfactory mode of measurement.

Attention has been cited as a significant factor in the increase of risk when driving (Hole, 2007; Kostyniuk and Eby, 1998). Attention is recognised as a complex cognitive function that involves alertness, memory and arousal, separate from conscious information processing that performs simultaneous operations even when consciousness is orientated

Chapter Two: Literature Review: Dementia and Driving:

elsewhere. (British Psychological Society, 2001; Grieve, 1993; Mirsky et al, 1991). The function of attention includes the ability to select relevant stimuli and ignore less significant information, the capability to monitor two or more tasks or stimuli and the maintenance of conscious focus upon a stimulus for extended periods (Knudsen, 2007; Theeuwes et al, 2004). Further, Egeth and Yantis (1997) propose two determinant factors that dictate where attention is directed. These are exogenous and endogenous. Exogenous cues such as unusual movement patterns, auditory stimuli or unexpected appearances of objects are monitored by the brain and prompt the need for more extensive analysis if required (Remington et al, 1992). Conversely, endogenous attention is planned and executed at the conscious level and can be intentionally and voluntarily directed to an object or situation. Exogenous cues upon attention can be overridden by goal driven endogenous influences (Egeth and Yantis, 1997).

Determining the precise role of attention in driving provides a significant challenge.

Research studies investigating the role of attention in accident involvement have attempted to evaluate the role of attention by using reports from drivers (Hughes and Cole, 1986).

Although studies such as those conducted by Hughes and Cole provide interesting information there are a number of problems with using a methodology that uses driver reports as a basis for results. Primarily, according to the definition of attention, a sizable proportion of the process is conducted beyond the conscious level and therefore the driver's recall of events probably does not correspond with where attention was directed.

Similarly, asking drivers to report items encountered such as road signs and environmental features skews the balance between exogenous and endogenous attention limiting the value of the data produced.

Chapter Two: Literature Review: Dementia and Driving:

A further cognitive element considered key to driving is that of executive function. The term executive function is used as a broad term to describe a group of cognitive processes and sub-processes. Executive functions are defined as those involved in cognitions such as solving novel problems, modifying behaviour in light of new information, generating strategies and sequencing complex actions (Elliott, 2003). Co-ordination, behaviour control and goal direction are also central to the concept of executive function. Executive functions are used to plan and coordinate sensorimotor responses to the complexity of environmental situations encountered when driving. The accurate encoding and integration of information must be available quickly to enable drivers to initiate a safe and appropriate response. Executive process enable drivers to respond appropriately in unfamiliar situations in which drivers are unable to rely upon well rehearsed or habitual patterns of behaviour and that involved technical difficulty above usual experience.

The DVLA guidelines, drafted by the Department for Transport (DfT) medical panel, state that individuals with poor short term memory, disorientation, lack of insight and judgement are almost certainly not fit to drive (DVLA, 2011). Carter (2006) also states that an impairment of either short term or long term memory is likely to render the driver unsafe. This guidance is however not supported by a significant amount of research evidence which suggest that memory is a poor indicator of safe driving behaviour (Apolinario et al, 2009; Dawson et al, 2009). Memory refers to the processes employed that acquire, store, retain and selectively retrieve information. A deterioration of memory however may be a more noticeable symptom of a more general and widespread cognitive impairment that subsequently impacts upon driving behavior (Apolinario et al, 2009).

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A cognitive element crucial to the driving task is that of visual perception. Visual perception is the process whereby all visual information captured by the eyes are organised, interpreted and assigned meaning (Grieve, 1993). The basic features of colour, depth, form constancy (the ability to recognise objects from different views and orientations) and figure ground (the distinction of an object from its background) all play an important role in the perceptual analysis of objects. The role of visual perception in driving is vital in enabling drivers to make swift, accurate and consistent interpretations of the environment and to plot a safe course through the hazards and obstacles encountered.

The integration of these cognitive components enable drivers to identify their own vehicle's position at any one time in relation to the environment and assess the distance between themselves and other objects, evaluating the velocity and direction at which both are travelling (Lundqvist et al, 2000). Safe driving is dependent upon the individual's brain to quickly and repeatedly assimilate the changes in information observed, recognising hazardous situations, and planning and executing a safe course (Lundqvist et al, 2000). Therefore, even the most modest reduction in processing capacity may have consequences for a person's ability to safely control a motor vehicle.

Models of Driving

To assist with the conceptualisation and analyse how drivers successfully integrate the components necessary to complete the driving task safely, a variety of models have been devised to aid in its understanding. These conceptual models have been heavily influenced by psychology and are frequently hierarchical in design (Simms, 1985). One of the most influential models in this field was designed by Michon (1985). Michon emphasised the failure to incorporate the results from the revolution in cognitive psychology as a major

Chapter Two: Literature Review: Dementia and Driving:

contributing factor to the relatively limited progress in driver behaviour modelling.

Michon's model divided the task of driving into three levels of skills and control. These levels include; Level one, or the strategic planning mode. This level consists of trip planning and the selection of appropriate routes. Level two, or tactical level is sometimes referred to as the manoeuvring level. This level focuses upon the driver's ability to negotiate the prevailing circumstances and includes obstacle avoidance, gap acceptance, overtaking, choice of gaps left between vehicles when following and speed selection. Level three, or the operational level, relates to longitudinal and lateral control of a vehicle, and focuses upon accelerating and braking and vehicle positioning on the highway. This model along with similar ones proposed by Mikkonen and Keikinen (1980) focussed mainly on performance aspects of driver behaviour. Later models that were based upon Michon's model tended to dispense with the route planning element and concentrated or refocused upon the motivational and tactical aspects of driving behaviour. This shift in emphasis allowed driving models to not only consider the physical performance of operation of the vehicle in certain traffic situations but also included the impact and importance of vehicles in personal development, purpose, environment and social context the driver is operating within (Barbera, 2004).

Perhaps the most immediate and apparent aspects of the driving task outlined by these models is that drivers must be able to identify their position at any one time in relation to the environment and assess the distance between themselves and other stationary and moving objects (Lundqvist et al, 2000). Different sources of information are utilised in making judgements of distance. These are partly the properties of the objects and environment and partly relating to the apparatus available for capturing and synthesising

the information such as lens accommodation, blur, eye vergence and stereopsis (Hole, 2009).

2.3 Conceptual Frameworks of Dementia:

The presence of dementia may be traced back beyond Plato and Horatius who recognised senile dementia as a state of madness influenced by old age (Boller and Forbes 1998). In the 19th Century a condition described as senile dementia characterised by forgetfulness developed legal and medical meaning (Berrios, 2011). It was however in 1907 that Alois Alzheimer published a paper describing a condition that now bears his name. The prevailing medical approaches conceptualise dementia as the physical changes in the individual's neuroanatomy. More specifically the degeneration of specific nerve cells, the presence of neuritic plaques and neurofibrillary tangles resulting in a reduction of cortex and white matter and consequently larger ventricles (Terry, 1976). Contrasting approaches however choose to consider mental illnesses, including dementia, as a social status conferred upon an individual by other members of the society.

Biological Perspectives of Dementia

From a biological perspective, dementia is a progressive disorder of impaired cognition and reduction in memory. The International Classification of Diseases (ICD -10) 2015 defines dementia as a syndrome in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. (World Health Organisation, 2015). Deterioration in memory, reasoning and communication along with a gradual loss of the skills required to carry out daily tasks are a significant feature of the disease. Other cognitive functions may

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include areas of planning, attention or abstract reasoning but may also include a physical element such as disorders of movement.

Within the dementia subtypes, Alzheimer's disease (AD) is the most common subtype of the syndrome with Lewy bodies (DLB), vascular dementia (VaD), dementia and Frontotemporal dementias (FTD) making up the majority of the remaining dementia syndromes (Scott and Barrett, 2007). These conditions are all age related with a prevalence estimated of 20 percent of those over the age of 85 displaying symptoms of the disease (Scott and Barrett, 2007). People diagnosed with Alzheimer's disease present with a combination of insidious memory loss and an accompanying focal cognitive dysfunction (Scott and Barrett, 2007). Progressive deterioration of cortical functions such as language, visuospatial skills, abstract reasoning, calculation, left-right disorientation and limb praxis are all clinical features associated with Alzheimer's type dementia. The onset of the disease typically occurs after the age of 45 but is more common over 65 years of age. Changes in behaviour and mood are frequent and hallucinations and insomnia are also occasionally associated with the condition. Functionally, the performance in instrumental activities of daily living tasks such as managing household finance, using the telephone and preparing meals tend to deteriorate as the disease progresses (Guk-Hee Suh et al, 2004).

Dementia with Lewy bodies is the second most common cause of neurodegenerative dementia in older adults (McKeith et al, 2004). The current diagnostic criteria for the probable diagnosis of dementia with a Lewy bodies require the presence of cognitive impairment together with two other clinical features that include hallucinations, fluctuations in mental state and extra pyramidal signs. The central feature of DLB is a

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progressive cognitive decline, pronounced fluctuations in attention and alertness, recurrent visual hallucinations and motor systems impairment such as bradykinesia and rigidity.

Comparative studies have suggested however that memory impairment in DLB is less severe than those in AD whereas visuoperceptual, visuospatial and constructional skills are significantly more impaired (Noe et al 2004).

Frontotemporal dementia (FTD) is characterised by focal atrophy of the frontal and temporal lobes. This subtype of dementia has three clinical variants; a behavioural variant where a change in personality and social conduct is more prominent and two language variants. An early feature of FTD is a loss of empathy or indifference towards others and an increase in apathy or lack of motivation may also be present. As the condition progresses the development of clinical symptoms such as overeating or dietary compulsions, repetitive or stereotyped behaviours, a reduction in attention to personal hygiene and hypersexuality are often a feature. Neurological symptoms such as bradykinesia, postural instability and rigidity are also frequently associated with FTD (Hoffman- Snyder 2005). The functional impact of FTD has been poorly researched. Individuals diagnosed with the language variants tend to present with a mild impairment in activity of daily living (ADL) function which appears to remain fairly stable (Thompson et al, 2005). Behavioural variant FTD by contrast characteristically present with a moderate to severe impairment in daily living functioning. The level of ADL impairment and rate of deterioration in behavioural variant FTD has also been demonstrated to be greater than that observed in Alzheimer's disease even after controlling for age and length of disease (Mioshi et al, 2009).

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Finally, vascular dementia (VaD) is a heterogeneous condition that encompasses many features and aetiologies. It is usually linked to cortical and subcortical ischemic changes resulting from systemic, cardiac or local large or small vessel occlusion. Vascular dementia frequently occurs together with AD posing a diagnostic challenge which has led to the term mixed dementia. Deficits are dependent upon the area of infarct/haemorrhage and can include motor, perceptual, language, visual and/or postural stability. Furthermore individuals are likely to have greater impairment of ADL function due to co-morbid illness.

Although the dementias are typically thought of as a disease of later life, early onset dementias are defined by the onset of the condition occurring prior to the age of 65 years (Quach et al, 2014). The prevalence of dementia in those under the age of 65 is reported to be 80/100,000. Approximately 40 percent of people diagnosed with early onset dementia are those with an AD type dementia (Quach et al, 2014).

Social Constructionism and Critical Approaches to Dementia

Being regarded as having a mental illness is wholly dependent upon social forces defining it (Pilgrim and Rogers, 1993). The act of defining an individual as having a particular status, such as dementia, leads to the labelling and subsequent associated behaviours towards the individual. For some, mental health labels are not indicators of physical status but rather judgements on human actions which impose particular consequences upon the individual such as hospitalisation, stigmatisation, denial of liberty and loss of independence (Davis, 2004). Criticisms of a burgeoning medicalisation of behaviours have come from a number of sources (Freidson, 2001; Pilgrim and Bentall, 1999). Social construction approaches challenge the biological perspective of mental health, arguing that

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diagnostic categorisations are simply constructs that have been historically generated and are now socially perpetuated (Harding and Palfrey, 2005). Critical approaches examine the ways in which power is ascribed to the medical professions. They question the pathologising of certain behaviours and are suspicious of the medical professions ability to mandate themselves as the only capable provider of treatment for the behaviours. Critical approaches to dementia focus upon repressive societal processes and the relative powerlessness of individuals with dementia. They are sensitive to the manner in which organisational powers such as medicine, law and culture operate to subjugate the person with dementia and argue that political, market and scientific organisations conceal systematic structures of dominance and oppression (Baltrušaitytė, 2003).

The departure from a medical understanding of dementia has continued and key developments at the centre of this movement are the concepts of personhood and social citizenship. This approach to dementia challenges the primacy of the biomedical model as a means to understanding the process of dementia. In discussing personhood in relation to dementia, Kitwood (1997) emphasised the importance of interpersonal relations of the individual and proposed that the decline in cognitive capacity, characteristic of dementia, was not solely a consequence of neurodegenerative changes but was often related to personal histories, interactions and the perception of others within the social context (Bartlett and O'Conner 2010). Although the concept of personhood represented a more socially centred means of understandings of dementia, it was not without its deficiencies. Primarily, personhood focussed upon the individual at the exclusion of more structural influences. It also failed to address the possibility of individuals influencing their own circumstances (Bartlett and O'Conner 2010). These elements were more fully addressed with the development of social citizenship in relation to dementia. Historically, the term

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citizenship has been used to describe the manner in which individuals relate towards each other within a society. Relations with people with dementia in Western culture continue to be dominated by discrimination and stigma. Social citizenship aims to promote full participation in society with justice and freedom from discrimination. It supports societal inclusion, promoting the right to shape events at a personal and societal level and arguing that the person with dementia has an equitable stake in personal and public life (Brannelly, 2011). Social citizenship is intended to influence approaches to dementia care and research by guiding personal interactions and structural approaches to dementia. The implementation of a social citizenship approach requires that people with dementia are meaningfully included, their potential for growth and positive involvement recognised, individual experiences given value and understood in the context of socio-political and cultural structures and finally, a fostering of a community and solidarity between people with dementia (Bartlett and O'Conner 2010).

2.4 Dementia and the Impact upon Driving:

The safety of drivers with dementia and older drivers in general is an ongoing concern for governmental agencies and the wider public (Hawley et al, 2010). The root of this concern does not appear to be based on evidence, much of which states that drivers below 80 years of age pose no more of a risk than the wider population (Box, 2010). Investigations and procedural reviews have been prompted in response to high profile cases involving older drivers and those diagnosed with dementia (Mitchell, 2001). As a reaction to these concerns the DfT have also periodically commissioned enquiries into older drivers and their safety. The most recent large scale review undertaken by Clark et al (2009) included information from three UK police forces and analysed accounts from over 2000 reported collisions involving drivers over the age of 60. The report concluded that no significant

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difference in safety existed for those aged 70 and below but that blameworthiness increased with age and those drivers over the age of 85 were four times as likely to have caused collisions. Blameworthiness was attributed from accounts obtained from police reports by the researchers using checklists. Judgement of blame evidently relied upon the reliability and accuracy of the records taken. The level and quality of detail varied extensively in the accounts. The value of data extracted from these accounts is questionable not only because of the disparities in the quality and amount of detail but also because it relied a great deal upon the researcher's skill in interpreting the accounts and a resistance to the influence of societal stereotypes of older drivers.

Driving safety of people diagnosed with Alzheimer's disease and other dementias will at some stage be affected by the condition sufficiently to require them to cease driving. In a review of dementia and driving safety Snyder (2005) estimates the manner in which the features of AD, DLB, VaD and FTD might affect driving safety. Impairments in memory were considered important in recalling details such as road regulations or geographic locations but more significant was considered to be elements of AD associated with the later stages of the disease process. These included anosognosia, executive dysfunction and visuospatial disturbance. The effect of executive dysfunction for drivers may not be immediately apparent but may only be exposed when required to react quickly to a novel or unexpected situation. This feature was illustrated by Rizzo et al (2001) using a small scale experimental study in which 18 participants with probable AD and 12 control participants without dementia undertook testing using a driving simulator. Testing involved participants driving a standard 15 miles route culminating in the driver's approach triggering an illegal incursion by another vehicle at a cross roads. Responses to this incursion were recorded. Although problems exist with the size of the study, the vagueness of diagnosis and the weaknesses associated with the use of driving simulators, the experiment produced results

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of some interest. One third of the participants with dementia collided with the vehicle, while all of the control group responses resulted in a safe avoidance. The authors concluded that the increase in the time taken to perceive the danger, plan the necessary response and execute the action resulted in an increased risk for some drivers with AD.

The impact of each dementia subtype specifically in relation to driving may not be entirely related to cognitive decline but may also include less familiar elements. Extra-pyramidal and physical symptoms such as tremor, postural abnormalities and dystonia may also be a significant contributing factor in compromising driving safety, particularly in the case of VaD and DLB. Physical impairments associated with all subtypes of dementia might also include limb weakness and praxis impairments, affecting the smooth operation of the vehicle controls.

2.5 The Evaluation of Driver Safety:

Concerns relating to driving safety are difficult to address for health professionals who frequently consider it an issue on or beyond the fringes of their clinical expertise (Brook and Southward, 2007; Frampton, 2007; Hawley et al, 2010). In an early but influential study Gillespie et al (1999) investigated the depth of knowledge and attitudes of geriatricians towards their responsibilities regarding the fitness to drive of their patients. The research was completed using a postal survey only of over 700 geriatricians practicing in the UK. The response to the study questionnaire was high, exceeding sixty percent, strengthening the results and reducing the likelihood of skew. The high response rate also perhaps reflected the relevance of this topic to practicing clinicians. The results of the study demonstrated that geriatricians are commonly reluctant to confront the issue of fitness to drive with individuals with a diagnosis of dementia owing to a lack of expertise

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and suitable information. The study identified that a significant proportion of the respondents advised individuals with a mild dementia to cease driving. Subsequent research has demonstrated however, that drivers with in the mild to moderate phase of dementia may remain safe when driving (Berndt et al, 2008; Brown and Ott, 2004). Although the study exposed widespread uncertainty of geriatricians in dealing with driving, the nature of the survey did not provide an opportunity for further exploration of the issues. In a later, large scale study constructed from a number of smaller studies, Hawley et al (2010) employed a mixed methods approach that included focus groups and semi structured interviews to investigate the attitudes towards fitness to drive with a variety of medical practitioners and medical students. This provided far richer evidence about attitudes of health professionals than was contained in Gillespie et al's (1999) study. The study sought to evaluate knowledge and attitudes of health professionals regarding driving and investigate how advice was provided. The key findings of the research mirrored those of Gillespie et al's study but further identified that medical practitioners received little or no training regarding driving and many did not routinely consider the issue of driving safety during consultations with their patients. Of those clinicians who provided advice regarding driving, a sizable proportion described uncertainty of procedural requirements and lack of available resources to enable effective decision making.

Instruments designed to detect decrements in cognitive function are used in many clinical settings. A variety of screening tools are available and used in the UK specifically to inform and support decisions regarding driving (Appendix B). Screening tools are designed to detect the presence or absence of a particular factor or to include or exclude a condition (British Psychological Society, 2001). Tools created to evaluate behaviours vary in their ability to act as reliable predictors to behaviour and there are no universally

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accepted clinical guidelines for what may constitute an effective assessment battery. To date, a number of driver screening tools are available but the development of a screening tool capable of reliably predicting driving safety has so far proved elusive (Kortling and Kaptein, 1996; McCarthy and Mann, 2006). Reasons for this are unclear but may be related to their over-reliance on cognitive testing. As discussed earlier, the components of cognition are largely conceptual and the manner of their organisation remains the subject of conjecture. Salthouse (2007) in an initial pilot study and second large scale study of healthy volunteers administered 16 different cognitive tests, not related to driving, on three separate occasions. The sample was grouped according to three age bands; young adult, middle and older aged. The results of the study found wide variation in an individual's test performance results over a relatively short period. The results also appear to demonstrate significant differences in cognitive testing performance across all age ranges tested. These findings emphasise the difficulties of identifying true changes from short term fluctuations and underline the need for evaluation tools to capture a more representative picture of an individual's function.

General Cognitive Screening Tools Used in Driver Evaluation

Testing tools designed to measure cognitive elements are frequently used to evaluate cognitive impairments upon driving. An example of this is the Trail-Making Test A & B (TMT-A&B) which was originally used by the American military to test general intelligence as part of the Army Individual Test of General Ability (Tombaugh, 2004). In the mid 1950's Reitan (1955) further developed the TMT to assess cognitive impairment of individuals with a brain injury. The TMT has been used to evaluate a range of cognitive elements such as general intelligence, memory and motor speed (Corrigan and Hinkley, 1987), visual perception, "fine motor abilities" (Groff and Hubble 1981), cognitive

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flexibility (Lamberty et al 1994) and visual scanning and attention (O'Donnel et al, 2010).

More recently the TMT has been used to predict the safety of driving of those with a cognitive impairment. In a meta-analysis of a number of small scale studies Silva et al (2009) illustrated that the test was not entirely predictive but demonstrated reasonable agreement with the performance of drivers on the on-road test.

The Mini Mental State Examination (MMSE) is one of the most frequently administered general cognitive screening tools used to provide an indication of the driving safety of older drivers with cognitive decline in both in the UK and the USA. The large proportion of research evidence agrees however that the MMSE may fail to predict driving competence in older people with a cognitive decline (Silva et al, 2009). In studies where MMSE test results were compared to both simulator and on road driving performance the predictive value of the MMSE was found to be poor (Adler et al, 2005). This may result from the MMSE's focus upon gross cognitive impairment, limiting its sensitivity to much milder impairments that can impact driving. It may also reflect the fact that the MMSE focuses upon language, orientation, and memory omitting other components of cognitive function such as executive processes that are important for safe driving.

Similar to the TMT and the MMSE, the Clock Drawing Test (CDT) is an established test and was originally used to identify visuo-constructional disorders associated with lesions sustained to the parietal lobe (Shulman, 2000). More recently however the clock drawing test has attracted attention for its role in the screening of early dementia and in particular Alzheimer's disease (Sunderland, Hill, Mellow, 1989). The test is reported to evaluate many of the cognitive components that are impaired in early cognitive decline such as memory, understanding of verbal instruction, spatial orientation, abstract thinking, executive and visuospatial skills (Aprahamian, et al, 2011). It has also demonstrated

reasonable success in identifying drivers who are unsafe to drive but has had less success in predicting safe drivers correctly (Freund et al, 2005).

Specific Driver Screening Tools

It has not been possible to evaluate all testing tools employed to assess driving capacity and therefore I have chosen to concentrate on tools that are in regular use in UK driving assessment centres (Inwood, 2007). A brief description of specific and non-specific driver testing tools has been provided (Appendix B). The Physicians Guide to Assessing and Counselling Older Drivers, (Carr et al, 2010) recommends the use of the Assessing Driving Related Skills (ADReS), (McCarthy, 2005), the clock drawing test (Sunderland et al 1989) and Trail Making Test. The ADReS tool has been designed for use specifically with older drivers. The tool is largely made up of cognitive tests but does include a vision and motor-function element. In an evaluation of the sensitivity and specificity of the ADReS screening tool, data were measured for levels of agreement with an on-road assessment. The study included 50 healthy volunteers sampled from a motoring club. The justification of the sample size was not outlined. Criteria for inclusion in the study did not require specific clinical diagnoses and although the research sample excluded individuals below the age of 65 only one person was included with a diagnosis of dementia.

Participants were informed that licensing authorities would be notified in the events of concerns regarding driving safety during the research and that this may result in loss of licensing entitlement. Perhaps as an effect of this and the sampling method used, very few participants were found unsafe to drive from the on-road assessment. Consequently, the results of the study must be treated with some degree of caution. Nevertheless, these results demonstrated that even with only a small proportion (16%) of the sample failing the in-car assessment, the ability of the tool to correctly screen safe drivers was questionable.

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The specificity, or the true negative results of the screening tool, was demonstrated to have a high degree of accuracy in identifying all those found to be unsafe on the road however the sensitivity, or true positives results of the screening tool, was extremely poor, incorrectly identifying 54% of participants as unsafe who subsequently passed the on-road evaluation (McCarthy and Mann, 2006).

Similar difficulties associated with sensitivity and specificity exists with driver screening tools developed and in clinical use across the UK. The Rookwood Driving Battery was originally developed by staff engaged in driving assessment, to provide an indication of driving safety and is used widely with a range of clinical diagnoses. It is now the primary screening tool used in driver screening across all diagnoses in the UK and for this reason I have considered its development and evidence for its use in greater detail. Three studies by the screening tool's principle developer have been published to evaluate and validate its use in assessing driving ability (McKenna et al, 2004; McKenna et al, 2007; Rees et al, 2007). These studies included participants totalling 735 participants although it is not clear whether these studies included the same participants or their data. The original research design used a sample of 142 participants with a wide variety of clinical diagnoses (McKenna et al, 2004). Sampling methods and inclusion criteria were not detailed. Participants were included if their medical condition "affected brain functioning". 43 participants were included over the age of 70 years and only 17 participants with a diagnosis of dementia. The participants were tested using the testing battery and then undertook an on-road driving evaluation. The on-road assessments were conducted by a driving instructor and the researcher. The driving instructor was informed of the cognitive battery performance before commencing the on-road assessment, weakening the study findings. The results of this study illustrated that the testing tool demonstrated good levels

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of sensitivity and specificity in relation to the on-road assessment when evaluating individuals with a traumatic brain injury, although statistical analysis was not used in calculating the level of agreement. When the results of participants with a diagnosis of dementia are taken in isolation however, the efficacy of the test is extremely poor. The sensitivity was calculated to be 0.54 and specificity, calculated to be 0.67. The positive predictive value, or the likelihood that the screening tool is able to identify unsafe drivers, was found to be 0.85 in individuals diagnosed with dementia and the negative predictive value, or the likelihood that the tools will identify safe drivers was 0.30. These results mean that the total predictive value for the Rookwood Driving Battery for individuals diagnosed with dementia in the four studies was little over 50%. Similarly poor results were obtained for those research participants over the age of 70 years. Results of testing also suggest poor outcomes in providing an accurate predictive indication for those individuals less than 6 months post brain injury or stroke. Finally, the nature of the testing tool, in particular the problem solving subtest makes the testing battery designed to be used on one occasion only. Retesting data has not been produced and no suitable resolution to the problem has yet been offered.

Explanations for the poor efficacy of screening tools to predict outcomes of on-road driving assessments are complex. The reliance upon measures of cognitive performance presents a number of difficulties. These include the lack of a full understanding of cognitive processes, their relationship with each other in normal function, the uncertainty of what specific functions cognitive testing tools are measuring and not least, their uncertain relationship with the driving task. The poor outcomes most testing tools experience with people diagnosed with dementia and those over the age of 70 years cannot be described simply in terms of the research processes used, although this cannot be

discounted. Almost all studies calculate levels of agreement of the testing tool with the on-road assessment. The use of the on-road assessment as a gold standard against which to measure testing tools should however be treated with caution. Many on-road assessments employ standard protocols but uncontrollable factors such as weather and lighting conditions, other road users and traffic volume may act as confounding factors limiting their use as an entirely reliable measure. Although practical alternatives to the on-road assessment may not exist, studies such as those conducted by Berndt et al (2008) have attempted to strengthen results by driving standardised routes, avoiding periods of heavy traffic volume and driving at similar times of the day.

2.6 Methodological Issues with Driver Research:

Researchers investigating the subject of driving and safe driving in certain populations encounter a number of specific methodological difficulties. I will provide a description of the foremost methodological strengths and weaknesses encountered by researchers when engaged in research relating to driving and in particular older drivers and drivers with dementia.

Ecological Validity

Research investigating driver behaviour often employs researcher observation of the driving task. This approach to investigating driving carries with it issues relating to the ecological validity of the data collected. One such issue is the likelihood that involvement in research or the presence of researchers or research apparatus will result in atypical behaviour. Drivers aware of the observation and evaluation of their driving behaviour are far more likely to adopt a more desirable driving style or as Orne (1962) termed, the demand characteristics of the experiment. This phenomenon may also have more subtle

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consequences. Much of the processes and skills used when driving are carried out on an unconscious level. The ability to divide and prioritise attention, identify potentially hazardous situations and respond is directly affected by arousal levels which are likely to be heightened under research conditions.

Associated with the problems of ecological validity is the element of artificiality of the driving task in studies. This varies in degrees from the use of simple driving simulators that bear little relationship to the driving task to experiments using actual vehicles. The use of simulators in driving research has expanded with the evolution of technology. Advanced simulators are now available that replicate the real world experience (Lunqvist et al, 2000). The advantage of simulators is that the external world can be entirely controlled and responses accurately recorded (Underwood et al, 2011). The quality of the simulators used in research is variable owing to the expense of larger more advanced pieces of equipment. The limitations of the simulator in research however are no longer restricted by technology but how humans respond to it. Drivers using a simulator are aware of the artificiality of the task and that their actions will have none of the consequences of real life driving.

Representativeness: Group and Geographical Differences

Representativeness, particularly in relation to older drivers is a difficult issue for researchers to address satisfactorily (Hole, 2009). Volunteers for research projects relating to driving are unlikely to have any concerns about their driving and are more likely to be confident that their driving skills are of a reasonable standard and remain intact. This may affect research in two ways. Firstly, for research using volunteer drivers as a control group, this may present an unrepresentative measure of normal driving and therefore exaggerating any results obtained from the experimental group. Secondly, if volunteers are used as the

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research participants, then results of the research may be unrepresentative and the problems of drivers underestimated.

Driver behaviour is influenced by the driver's environment (Chen et al, 2009). Differences in driver experience and in the traffic volumes to which they are regularly exposed may well influence their performance in research. City centre driving and rural road systems demand different skills when driving (Sunbury, 2010; Zwerling et al, 2005). City centre traffic systems involve complex junctions and traffic signalling, multi-lane carriageways and one way road systems. Traffic volumes are frequently high and demand close interaction with other vehicles of differing sizes and speeds, whereas drivers more accustomed to driving in surroundings with fewer vehicles and junctions and in a much less complex traffic environment are likely to develop an entirely different set of driving skills.

Accident Statistics, Accidents Causation and Exposure Rates

Many of the research projects investigating driver behaviour have used accident statistics as a measure of driving performance. Research data gathered from accident statistics infer links between the driving behaviour or group characteristics and the prevalence of collision. The value of the research using accident statistics is entirely dependent upon the quality of the reporting of the incidents. The manner in which accidents are reported is variable across agencies and geographical locations making direct comparisons extremely difficult (Hole, 2007). The data used within these studies is heavily reliant upon the quality of reporting at the time of the incident. Road traffic accidents also very rarely result from a single cause, but are rather the consequence of a number of converging factors. This makes attributing blame to a single source or person extremely difficult. In situations where blame

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is unclear, the role of stereotyping may have some influence upon the accident statistics. This is an important consideration especially when considering research involving older drivers who may be assumed to have, reduced driving skills and poorer reaction times.

2.7 Chapter Summary:

This chapter has examined the elements that comprise the driving task, the diagnosis of dementia and the manner in which dementia may affect satisfactory driving performance. Driving has become central to the maintenance of independent functioning, especially for people with a limitation in their personal mobility. The complexity of the task requires full integration between physical, sensory and cognitive elements of functioning. The diagnosis of dementia need not lead to an immediate cessation of driving as many people with a diagnosis of dementia continue to drive safely. The effects of social attitudes and negative stereotyping of older age and dementia however may influence decisions regarding continued safe driving. The progressive nature of cognitive and physical decline will nevertheless result in decrements in functioning that will ultimately lead to driving becoming unsafe.

The chapter has demonstrated that the use of purely cognitive measures in constructing driver screening has, to date, been unable to provide reliable and clinically useful tool, particularly in the field of dementia care. Current strategies for detecting decrements in driving ability remain fragmented and inconsistent across healthcare, frequently resulting in poor guidance and inappropriate interventions. Approaches taken in the development and validation of driver screening tools have employed research designs that do not take into account methodological difficulties unique to the topic of driving. This research project adopts a unique approach to the development of the screening tool and in doing so,

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seeks to offer a screening tool sensitive to the changes and fluctuation brought about by the diagnosis of dementia. The next part of the thesis describes the methodological considerations that shaped the study.

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Chapter Introduction:

The purpose of this chapter is to present the reader with an explanation of the broad theoretical approaches and practical elements underpinning the decisions made in the design the study. It will describe the cultural and political factors influencing the decision to locate this study within the critical research paradigm and detail the elements enabling individuals taking part in the project to explore the topic and address the research aim. The chapter will examine the issue of participation and evaluate the strengths and weaknesses associated with participatory approaches to research projects. The chapter concludes with a discussion of trustworthiness and quality in relation to the approach used and examines the judgement of quality in relation to the project.

3.1 Selecting the Research Approach:

The fundamental aim of this research project was to utilise the group's expertise and experiences to inform the development of the driver screening tool. As demonstrated through the review of the current literature, current testing instruments are especially unsatisfactory when addressing the driving of older adults and those with a diagnosis of dementia. Approaches to the development of these instruments have, without exception, relied upon the clinical knowledge and expertise of clinicians to structure the question, locate the particular components of the cognitive skills used in driving and create satisfactory measurement indicators that identify when decrements in driving safety exists. This has resulted in approaches to their development following broadly similar patterns with predictably similar results. Much of the previous work carried out in designing testing instruments has been conducted using neuropsychological approaches and testing

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principles which have drawn heavily upon positivism. The problems encountered by people diagnosed with dementia can be transient and multi-dimensional and therefore difficult to locate using positivist approaches. A research approach that gave voice to the experiences of individuals with understanding of living and working with people with a dementia was considered vital in revealing aspects of the condition that may indicate difficulties with driving.

Research Paradigms

Approaches to enquiry have been seen to include two broad, largely divergent and competing views about the fundamental nature of knowledge. These paradigms are not strictly delineated and competing but can be broadly referred to as positivism which is typically associated with quantitative approaches to research and interpretivism which is more readily associated with qualitative research strategies. These paradigms have opposing ontological foundations and epistemological mechanisms for investigating and explaining these foundations by means of specific methods. This research project will look to interpretivism for its ontological reference and more specifically to social constructionism for its epistemological underpinning. Social constructionism is a theoretical body of knowledge that addresses specifically the ways in which societal groups develop, interpret and construct the reality in which they operate (Berger and Luckman, 1967).

The origins of social constructionism are rooted in the postmodernism movement which resonates throughout the approach to this research project. Postmodernism is used as a broad term to describe a movement that encompasses artistic as well as sociological themes. The central tenet of postmodernism is a questioning and rejection of the essential

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assertions of the modernist movement, in particular the meta narrative of science (Lyotard, 1996). The influence of postmodernism upon the development of social constructionism is most evident in the role of power, and discourse and the scepticism of absolute truths and realities being constructed and sustained within groups of individuals. A single unifying definition that serves to describe and explain social constructionism has not met with universal agreement. Rather, the approach shares broad commonality in key areas. Social constructionism requires that a critical approach is taken to existing knowledge of our world and of ourselves. It demands critical analysis of the world and challenges the principle that our observations provide us with an objective account of our surroundings (Burr, 2005).

Social constructionism emphasises the ways in which the world is both conceptualised and categorised and is historically and culturally specific. Understanding of the world is accomplished and determined through a range of internalised constructions such as gender, class, race and culture. Knowledge is constructed, developed and sustained within society and by personal interactions (Nightingale and Crombie, 1999). The approach adopted in this research will be of critical realism. This branch of social constructionism is distinct in that it asserts that a reality exists independent of our thought and perceptions. Critical realism acknowledges that although our thoughts and perceptions are not an accurate representation of reality, they do reference it in some way (Hrbuy, 2001). Physical and social organisational systems operating simultaneously serve to reinforce and constrain our thoughts, actions and language (Houston, 2001).

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Cultural and Political Element

A central tenet of the social constructionist perspective addresses the ways in which common understandings and categorisations of the world are historically and culturally defined and structured and sustained by social processes (Burr, 2005). Social constructionism also suggests that social constructions or knowledge brings with it a variety of social actions. These features of social construction are shared with critical approaches to research. The critical theory movement was a product of the Institute of Social Research, which was the first Marxist influenced research institute in Germany (Kellner, 1989). Broadly, this movement commented upon all spheres of human existence that oppressed or subjugated and sought solutions that would serve to liberate and emancipate. Critical theories reject the assumption that freedom is identified with a particular institution or system of thought and are deeply suspicious of tradition and all absolute claims (Berman, 1989).

Critical approaches to research similarly focus upon the influences of history and structure, social actions or praxis and the deconstruction of social processes in explaining the organisation of social practices. The focus of critical approaches however emphasise issues such as power, oppression and emancipation in their objectives. A key element of research approaches that acknowledge critical factors is an acknowledgement that all understandings are constructed and mediated through the prism of the dominant perspectives of the society. Critical approaches are therefore in essence emancipatory and intended to empower oppressed social groups. This connection can be seen in Paulo Freire's work (1970) which explores the dehumanisation of oppression and the "conscientisation" of individuals through a process of critical thinking.

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Freire's approach to education was created in the context of a period of political instability in Latin America. Freire's use of the word is intended to suggest an awakening, or a enabling of consciousness referred to as "conscientisation" (Crotty, 1998). Freire proposed that that a variety of social structures created and maintained a pervasive discourse of oppression that is perceived as being outside an individual's control resulting in helplessness, apathy and acceptance. The key to conscientisation according to Freire is the recognition of the relationship between humans and their world, or as Freire states, humans are not only 'in the world' but also 'with the world'. In expressing this view, Freire makes reference to phenomenology and in particular the work of Brentano and the concept of intentionality. Intentionality refers to the relationship of the consciousness and objects. It proposes that the world in which we inhabit is neither wholly created by our conscious or exists entirely independent of it. Rather it is our consciousness that engages, shapes and gives meaning to our outside world (Lyotard, 1996). Using intentionality, Freire aimed to enable a critical understanding and empowerment of one's own position, or as Freire explains it, a realisation that human being are called to be re-creators of the world not just mere spectators (Freire, 1972). In developing the research approach I have been mindful of the role of the individuals taking part and aware of the pervasive discourse of western medicine. The design of the research was intended to lessen the influence of the researcher/participant, health professional/patient relationship and giving voice to the individual's own experience.

Power and Discourse

The notion of power has been defined in a number of ways that overwhelmingly view power as a force that can be exerted by one individual over another. Power has been framed as force, influence, effectiveness and acceptance of authority (Behuniak, 2010).

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The concept of power as described by Michel Foucault is not simply a tool used to subjugate but is rather a complex network that pervades each individual forming their learning, attitudes and discourses (Foucault, 1980). Associations to critical and social theories have been greatly influenced by the work of Michel Foucault. Foucault suggests that discourse relates not just to verbal or written communication but to systems of thought which are constructed from ideas, actions, beliefs and practices that systematically build the worlds to which they relate (Lessa, 2006). In this way then, power and truth are key to discourse. For Foucault truth was not an objective entity but rather:

Truth is of the world: It is produced there by multiple constraints... Each society has its regimes of truth, its general politics of truth: that is the types of discourse it harbours and causes to function as true: the mechanisms and instances which enable one to distinguish true from false statements, the way in which each one is sanctioned; the techniques and procedures which are valorised for obtaining truth; the status of those who are charged with saying what counts as true.

(Foucault in Mills, 2003, p.18)

Truth is therefore something which societies negotiate and develop in a structured manner rather than existing as a discrete entity. Similarly, Foucault's approach to power does not view it simply as an objective item that may be possessed, seized or relinquished, rather, it is dispersed throughout social interactions. Linked closely to this idea, Foucault also rejected the proposition that power is used to repress or an expression of economic relations. Foucault believed power to have positive elements that were widely dispersed across the social system, capable of producing forms of behaviour as well as being restrictive. Considerations of these factors were crucial in the development and process of this research project to enable and facilitate people's active involvement. The fundamental obligation for researchers using this approach is to take account of the political, historical, class and social influences upon beliefs and actions, at every stage of the research.

3.2 Selecting the Method:

Social construction and critical approaches will be used to inform the research process in particular with a focus upon old age and dementia. Consideration will be given to the construction of aging, particularly under western capitalism, as the primary cause for the marginalisation of older people. This research will acknowledge that the criteria and factors acting to determine quality of life for older people are identical to those that influence the wider population (Hughes, 1995). It also acknowledges that the experiences of older people are affected much more by economic and social factors, and that political and market forces have served to reinforce systematic structures of domination and oppression (Moody, 1992). By basing the epistemological underpinning of the study with critical realism and critical theory, the research project will not, as others have done, use labelling and stereotyping as its foundation or starting point. The project is designed to value and utilise the input of those taking part and will be mindful of the potential of oppressiveness in behaviours and roles.

Public and Patient Involvement in Healthcare Research

The move towards a greater involvement of lay people in the organisation and research of health care has gathered momentum over the last two decades. Successive UK governments have recognised the value of building in user perspectives when planning national and local services (DoH, 2003). The significant structural changes within the NHS, proposed in July 2010, lay particular emphasis on patient involvement and shared decision making in healthcare provision. (DoH, 2010; NIHR, 2010). The value of public involvement to services and research, it has been argued, is that it better equips services to identify and respond to local needs and that service provision is far more likely to be

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democratic and accountable through the inclusion of local membership (Florin and Dixon, 2004).

Involvement in UK healthcare research has been defined as:

An active partnership between patients and the public and researchers in the research process, rather than the use of people as 'subjects' of research. Patient and public involvement in research is often defined as doing research 'with' or 'by' people who use services rather than 'to', "about" or 'for' them. This would include for example, the involvement in the choice of research topics, assisting in the design, advising on the research project or in carrying out the research.

(NIHR, 2011. p.4)

The nature and level of this involvement has nevertheless been contested. The involvement of service users in research at each stage from setting the agenda to disseminating the findings has clear benefits in ensuring research is sensitive and meaningful for the population. The use of involvement in health care organisation and research has attracted criticism for the actual level of influence brought about by the inclusion of lay members. Much of the criticism centres on whether the levels of involvement are in fact tokenistic. Involvement, it has been argued does not necessarily lead to empowerment (Cornwall, 2008; Schultz et al, 2003). The term involvement is extremely broad and may cover many approaches, levels of participation and degrees of influence (Moore, 2006). This is further complicated by the relationship of the individuals with the organising institution. For example certain individuals with disabilities and users of mental health services do not consider the label of patients represents them positively, as this term suggests an element of passivity (Baggott, 2005). Relationships in health care may be one of patient, service user, citizen or customer, each of which suggests a differing relationship with the research body. Essentially however, the discourse and distribution of power in relation to health care makes full and equitable participation in service organisation, provision and research

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almost impossible since expert knowledge and control of the research project largely rests with the health care employees and researchers.

Participatory Action Research

The process of exploring and acquiring data that is relevant and useful in the development of the screening tool will necessitate the active involvement of groups with experience of dementia. The approach adopted for this project will therefore draw upon Participatory Action Research and related approaches to inform the design and approach of the researcher. The following section will explore participatory approaches in greater detail and will describe the basis for its selection for my approach to the research.

A variety of participatory approaches to research enquiry exist. Broadly, participatory approaches advocate the active involvement of individuals to varying degrees in the research process. These approaches range from projects designed to bring together a collection of individuals with a connection to the subject to address a specific topic, to fully collaborative enquiries that negotiate and agree the entirety of the process from defining the area of enquiry to the dissemination of the findings (Kemmis and Taggart, 2005).

Participatory action research has its roots firmly planted in action research. The genesis and development of action research cannot be located from a single source. It is accepted however that the work carried out by Kurt Lewin in the 1940's resulted in the term action research and much of the blueprint for conducting participatory research (Robson, 1993). The democratising and collaborative philosophy of action research set it apart from more traditional and dominant scientific forms of research of the day. From this epistemological position action research aimed to combine praxis, theory and reflection in a collaboration of researcher and researched (Reason and Bradbury, 2001). Lewin developed this

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theoretical approach over a number of years. Action research has been defined by Reason and Bradbury (2001, p1) as:

A participatory democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participatory worldview... It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities.

Action research was a development in social research, resulting from the inadequacies of the more traditional research techniques that were laboratory based. Traditional research techniques established the researcher as an independent observer of events in the interests of objectivity. The rationale for this type of research was to observe but not influence events. Action research however actively encourages change and promotes changes in outcomes and new understandings. The action research approach accepts and embraces the role of the researcher in the process of change and formalises the means in which change or action may be achieved (Robson, 1993). This process of conducting action research was initiated by beginning with a focus subject that requires change. The fundamental elements of the action research process have been refined and expanded by subsequent theorists but essentially include, planning, action, observation or reflection and evaluation of the action (Kemmis and McTaggart, (2005). This process is not intended to be a linear but is cyclic and is illustrated below:

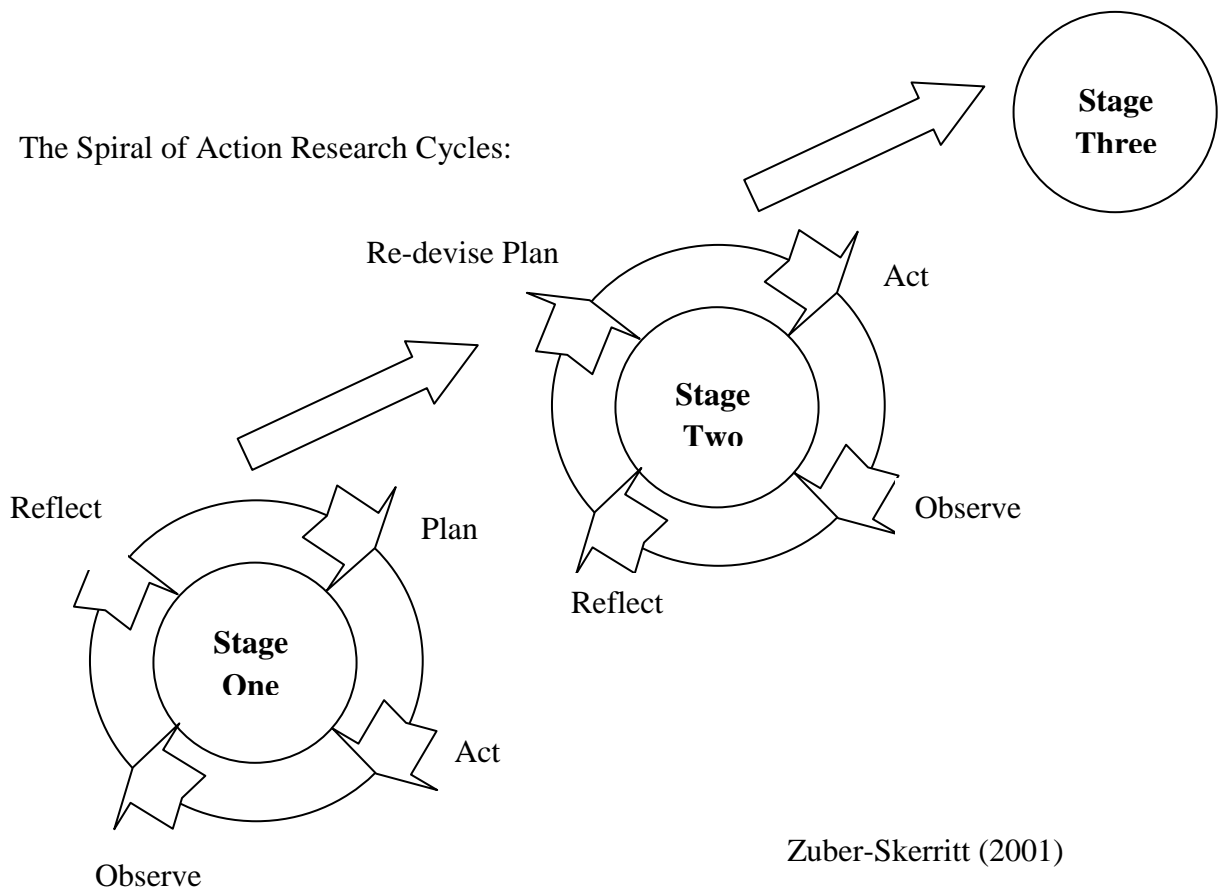


Figure 2

From its birth action research has been adopted and adapted for use in many settings. The shift in the function of the researcher and the principles of facilitating change, using a reflective cyclic process and the active involvement of the people and groups has influenced research approaches and created many branches of action research.

Participatory action research (PAR) is a branch of action research that proposes individuals be considered both research participants and co-researchers. This approach is a divergence from traditional action research but has its basis firmly within Lewinian philosophy that asserts that any investigation of the elements of human behaviour are likely to contain greater meaning and relevance if the individuals concerned are closely associated to the testing and building of changes (Argyris and Schon, 1991). A key of PAR is the belief in its ability to subtly explore individual perceptions and locally held knowledge (Altrichter et

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al, 2002; Kemmis and McTaggart 2005). Active empowerment in the research process not only increases the relevance of the process and the outcome but also creates practical benefits for those taking part (Alexander, 2010). Participatory research considers a rebalance of power in the research process through active participant involvement (Minkler and Wallerstein, 2003). In doing so it not only encourages greater involvement from those taking part in the research but necessarily reduces the power, influence and control held by the researcher and asserts that the subject expertise does not necessarily lie solely with the researcher.

The approach adopted by Paulo Freire illustrates the nature of the participatory relationship. Freire's approach invested trust in the oppressed to reason and participate in change:

A revolutionary leadership must accordingly practice co-intentional education. Teachers and students co intent on reality are both subjects, not only in the task of unveiling that reality and thereby coming to know it critically, but in the task of re-creating that knowledge. As they attain this knowledge of reality through common reflection and action, they discover themselves as its permanent re-creators. In this way, the presence of the oppressed in their struggle for their liberation will not be what it should be: not pseudo-participation but committed involvement.

(Freire, 1972, p. 51)

It was Freire's belief that a donor/recipient relationship in finding solutions for individuals not only serves to reinforce existing power discourses but results in the imposition of irrelevant solutions. Oppression inhibits the freedom to create, venture and construct. The relationship that individuals form with the diagnosis of dementia is mediated by social constructs and stereotyping of the condition. It is also informed by the medical support and interventions received. Both of these agents of society are extremely powerful in determining the relationship with the condition. According to Freire's perspective, for

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empowerment or emancipation from social constraints to take place, individuals must play an active and responsible part in the act of exploring solutions.

Participatory methods advocate a “bottom –up” rather than conventional “top-down” approach to the investigation practices. Bottom-up approaches refer the piecing together of simple information to create broader theories as opposed to top down approaches which use the wider concept as a starting point for investigation (Löfman et al, 2004). PAR also advocates that the focus of the research be action rather than knowledge generated simply for understanding. Cornwall and Jewkes (1995) illustrate the differences between conventional research methods and those of PAR. A comparison of the research processes of PAR and conventional approaches are illustrated in the table below.

Table 1

Participatory and Conventional Research: A Comparison of Process		
	<i>Participant Research</i>	<i>Conventional Research</i>
What is the research for?	Action	Understanding with perhaps action later.
Who is the research for?	Local People	Institutional, Personal and professional interests
Whose knowledge counts?	Local People's	Scientist's
Topic Choice Influenced by?	Local Priorities	Funding priorities, Institutional agendas and professional interests
Methodology chosen for?	Empowerment, mutual learning	Disciplinary conventions, "objectivity" and "truth"
Who Takes Part in the Stages of the Research Process?		
Problem Identification	Local People	Researcher
Data Collection	Local People	Researcher, enumerator
Interpretation	Local concepts and frameworks	Disciplinary concepts and frameworks
Analysis	Local People	Researcher
Presentation of Findings	Locally Accessible and useful	Researcher to other Academics or Funding Body
Action on Findings	Integral to the Process	Separate and may not happen
Who takes action?	Local people with/without external support	External agencies
Who owns the results?	Shared	The researcher
What is emphasised?	Process	Outcomes

Source: Cornwall and Jewkes (1995, p.1669).

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Although the core principles remain static, participatory methods have been tailored to specific use in many fields of enquiry. The table above clearly demonstrates the rationale for selecting a participatory approach in preference to other research approaches in meeting the need for the research to actively generate a screening tool directly from the experiences of those taking part.

Community Based Participatory Research

Research carried out in the field of health carries its own unique challenges and demands. This is especially true of participatory approaches. Community Based Participatory Research (CBPR) has been developed for use in the field of public health, nursing and social work with the aim of integrating knowledge with interventions and policy change (Israel et al, 2005). It has been used specifically in the health care setting with the aim of improving community health and eliminating health based disparities. The genesis of CBPR was a direct development from PAR approaches and evolved from participatory research carried out in the field of health and social care. The aim of CBPR incorporates the principles of collaboration, action and empowerment within the research process and is described as serving to: “increase knowledge and understanding of a given phenomenon and integrate the knowledge gained with interventions and policy and social change to improve the health and quality of life of community members” (Israel et al, 2003).

The value of a more participatory approach to research and development of research projects that increase involvement of individuals with dementia is acknowledged (Harrison & Brandling, 2010). A key reason for the paucity of research in which people with dementia played a more active role has been attributed to the limited understanding and experience of participatory methods by researchers (Wilkinson, 2002). This research

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project will draw upon the primary principles of CBPR, described by Israel (1998, 2003, 2005), in achieving its research goals. These principles although broad can be applied specifically to research in the field of dementia. This is illustrated below in a table that details reflexive questions researchers are directed to consider before embarking upon research with individuals diagnosed with dementia (Bartlett & O'Conner, 2010). The table illustrates how CBPR principles can be directly applied in answering these questions.

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Table 2

Reflexive Questions to Set in Motion a Participatory Approach in Dementia (Bartlett & O’Conner, 2010, P.104)	Principles of CBPR (Israel, 2003, 2005)
How do you create alliances with people with dementia and how do people with dementia create alliances with you?	Acknowledges group as a unit of identity.
How can you place your methodological expertise in the hands of those who may wish to use research to combat stigma and discrimination?	Identifies and builds upon the strengths of the group.
Who do you feel accountable to – people with dementia, your employer, funder?	Promotes collaborative, equitable, partnership in all phases of the research, encouraging group responsibility
Who has power over your research activities?	Fosters Co-Learning and Capacity Building Among Research Partners
Will research the research serve only the interests of those who have power?	Focuses upon the local relevance of public health problems ensuring research is meaningful and for the mutual benefit of all partners.
How might you modify procedures and techniques to enable participation?	Involves systems development that using a cyclic and iterative process
What can you do to ensure people with dementia are involved in the dissemination of findings?	Disseminates results to all partners and involves the in the wider dissemination process
What has changed for people with dementia as a result of your research?	Involves long term process and commitment to sustainability.

3.3 Participation of Whom and to What Degree:

In completing this research project I was confronted with two dilemmas resulting from decisions regarding the level of participation of those taking part. Firstly, was the degree to which researcher influence could be relinquished and secondly, the degree to which individuals with a diagnosis of dementia might participate without placing them at risk. These components are evidently closely linked but each included their own specific considerations. The degree to which the researcher devolves the power to those involved in the research varies. Levels of involvement are influenced by a number of factors. The degree to which individuals are involved in the research process takes on added significance when the individuals are considered vulnerable.

Researcher Participation: The Student Researcher Dilemma

A variety of models exist detailing levels of control in the participatory research process. Cornwall and Jewkes (1996) developed a continuum of involvement moving from the less desirable to the ideal participatory model. This hierarchy of participation places a relative value upon the study according to the degree of participation assumed by the individuals involved in the study. The greater the degree of control exerted by the researcher in designing and carrying out the research, the less desirable the approach is considered to be. This approach is, in many ways, incompatible with a study undertaken as part of an academic award in that the primary focus of the research must be successful completion of the academic programme. Doctoral theses are necessarily works of originality and are owned entirely by the author and are used as an indicator of the author's ability. Heaney (1993 p.45) expresses this dilemma well;

The researcher must have control over the research from start to finish. Timing is critical. A doctoral student working on a dissertation cannot afford the luxury of working with a community on a community's timetable and with the possibility that

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the project will be called off or take a different set of goals, in fact, become a different project.

Limitations of researcher resources, in relation to physical, financial and expertise also prohibited a large scale project that enabled individuals involved to undertake educational training relating to the research process, define the research scope and aims and complete the research project.

Group Participation

The drive towards an involvement of people with a diagnosis of dementia in research is increasing and the supposition that the diagnosis of dementia naturally eliminates people from taking an active role in research is being vigorously challenged (Bartlett and O'Conner, 2010). The involvement of people with dementia in research and more specifically, in research that is employing a participatory approach, present a number of significant challenges. Given the problems associated with dementia, discussed in Chapter Two, a number of issues require detailed consideration in the design of the research. Primarily, researchers must be conscious of the demands placed upon individuals involved in research. Studies conducted over a period of time must incorporate monitoring and response strategies to account for the deteriorating nature of the condition. Difficulties associated with expressive and receptive communication may have an effect upon an individual's ability to participate fully, especially when confronted with the specific language-set of the research process. Participatory methods also present their own particular collection of dilemmas. Research designs intended to empower those taking part may in fact place unreasonable burdens upon individuals. Responsibilities to the research process and expectations of fellow researchers may be unsustainable for the individual with

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dementia. For people with a diagnosis of dementia contributing meaningfully to a participatory research project, the balance between excessive and harmful demands and that of a purely token involvement is an extremely delicate one.

Solutions to the Question of Participation

The initial intention when conceptualising the research project was to explore the use of an entirely participatory approach, as advocated in CBPR. As described earlier, for this research and, it may be argued, most other research projects, to use an entirely participatory approach to the study was neither possible nor indeed desirable. The resolution to the dilemma of researcher control and group involvement in this study was discovered in the early recognition that some amount of control and ownership of the project needed to be retained. From this point, the balance between group participation and researcher control was considered and continually reviewed at each stage of the research process. To assist with determining the most suitable approach to participation, typologies of participation were considered.

The collaborative nature of the participatory involvement in this study has been categorised as providing an appropriate degree of participation according to Arnstein (1969). This model describes a ladder or hierarchy that range from citizen control through to non-participation. Arnstein's model places partnerships and collaboration in preference to consultation. Partnership according to Arnstein's model remains in the broad category of citizen power and therefore considered legitimately participatory in nature. Arnstein's model is however extremely broad and fails to consider the range of involvement that may qualify as partnership. A detailed description of participation was given by Pretty (1995) and was used to further examine the manner of involvement of individuals involved in this

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study. This model included seven modes of participation that ranged from on the one hand, manipulative participation which indicates an approach employing deception and a pretence of participation to on the other hand self-mobilisation where individuals participate independently of external institutions to conduct research or take action. The level of participation for people taking part in this study, according to Pretty's model, falls within the functional and interactive participation categories which are positioned towards the desirable end of the continuum. The essential factor in determining this is that although the aims of the study have been constructed externally, the active involvement is considered essential and a right of group members. My role in this research is restructured from that of director of the project to one of catalyst of group functioning. This approach to research participation and researcher role has also been similarly categorised by Stoecker (2003) who labelled this mode of researcher influence as an initiator.

The primary aims and parameters of the research were set prior to meeting with the participants. During the research process, participants were offered the opportunity to accept collaborative responsibility of deciding research priorities, development of the emerging data, and ultimately the creation of the screening tool. The setting and maintenance of the basic parameters ensured that the research remained centred upon the broad topic of driving and dementia while enabling scope for unstructured discussions and development of the final tool. The approach taken in this research also enables sufficient control of the process to ensure timely completion and a satisfactory level of ownership while satisfying the demands of a participatory approach to the project.

Participatory Research; a Critique

Participatory approaches to research have received criticism from a variety of quarters.

The capacity of participatory approaches to empower and emancipate those taking part has been questioned. Kemmis and McTaggart (2005) explain that researchers employing participatory approaches have fallen victim to an enthusiasm to involve individuals in the research process but without the practical means of meeting their aims. Kemmis and McTaggart argue further that changes brought about by such research are frequently constrained and inauthentic. A true change to an individual's condition requires structural and sustained support. This criticism has theoretical parallels with Habermas's conceptual representation of emancipation being the complete correction of all societal distortions (Rasmussen, 1999). In contrast, Michele Foucault (1980) insisted that the measure of emancipation is the individual's ability to construct one's own values. Foucault urged that individuals construct themselves aesthetically against institutional power (Nuyen, 1998). This evidently has significance for participatory research methods in that emancipation or empowerment, according to Foucault, is not entirely dependent upon societal change but has an element of self determination that is influenced by creative involvement and constructions of personal knowledge and beliefs.

Participatory approaches to research have also been criticised from proponents of emancipatory research who state that participation does not necessarily lead to empowerment or a stake in the research process. Zarb (1992) examined the differences between emancipatory and participatory research in relation to people with a disability. He acknowledged that a participatory approach involves people in a meaningful way and is useful in that it makes researchers 'available' to (disabled) people but was of no more value than that. Increasing the level of participation cannot move the research from participatory

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to emancipatory unless it is the people themselves who are controlling the entire research process.

3.4 Trustworthiness and Quality:

An enduring concern for researchers conducting research that employs qualitative methods is how the data analysis and results of the research are legitimised and defended. The traditional positivist measures of the quality of research projects are in the main irrelevant and inappropriate for research that adopts a constructionist approach. Further, criteria such as reliability and validity are of questionable value for this research project because knowledge is considered to be provisional and contestable and material data historically, culturally and personally dependent. Indicators of research quality have been formulated specifically for qualitative or naturalistic approaches to research. For example Lincoln and Guba, (1985) proposed criteria of credibility, transferability, dependability and conformability should be used to evaluate the quality of naturalistic research. This approach has been used widely in the field of social science, but owing to a significant association with the criteria used in positivist enquiry method, fails to address entirely the issue of trustworthiness for this research project. Although important to the value of the research, evaluations of quality that extend beyond the procedural fitness of the process are necessary. The criteria used to evaluate the quality in relation to this project will also need to consider factors such as the aesthetic significance, ethical dimension, reflexive content and the expression of a historical and cultural reality.

Bochner (2000) suggests that criteria for judging the quality of qualitative research include more than scientific considerations. Bochner argues that although differences exist between modernists and postmodernist, empiricist and interpretivists, inevitably choices are made

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between what represents good quality and useful research and what does not. Bochner argues criteria relating to quality have as their subtext an oppressive element that serves to stifle subjectivity and promote rationality, adding that social science research may include the measures of methodological rigour but that it also demands an element of artistry and appreciation of the political, ethical, and personal sociology.

Finlay (2006) suggests that owing to the wide variation in qualitative methodological approaches and epistemological underpinnings that fixed evaluative criteria of trustworthiness and quality are of limited value. Rather, the methods used are likely to dictate the most suitable evaluative criteria and combinations of criteria are practically useful. Finlay suggests researchers consider five broad categories relating to trustworthiness. The categories include whether the research made contextual sense and whether a convincing argument was constructed. It also encourages consideration of the contribution the work makes to the field and whether the research has resonance with the reader's experience. The final criterion scrutinises whether adequate respect and sensitivity has been demonstrated towards those taking part (Finlay, 2006). A broader approach is proposed by Ballinger (2004) who suggests criteria for researchers working from a relativist position. These include reflexivity, or thinking critically about actions and perceptions, transparency or the degree to which all research practices are detailed and utility or the degree to which the research has an impact either theoretically or practically (Ballinger, 2004). Ballinger's broad criteria have been used primarily owing to their specific relationship with the epistemological approach to the study and specifically the acknowledgement of multiple possibilities of understandings. Used in isolation as a guide to trustworthiness, these criteria were considered to be insufficiently precise and lacking in satisfactory detail to guide and evaluate the quality of the study. Ballinger's work was

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included however because the criteria's breadth reflected well the reflexive nature of the design and the anticipated utility of the study outcomes. They also acted as broader headings for the more detailed models used. This is illustrated in the table below.

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Table 3

Trustworthiness and Quality Criteria		
Finlay (2006)	Bochner (2000)	Ballinger (2004)
Clarity	Details.	Transparency
Credibility	Individual's stories reflecting past and present.	
Contribution	A story that has an emotional as well as an intellectual impact.	Utility
	The researcher must meet a demanding standard of ethical self consciousness.	
Communicative Resonance	Researcher's honesty and emotional credibility.	Reflexivity
Caring	Detailed journey from who I was then to who I am now.	

Utility as a Determinant of Quality

In ensuring the overall quality of the research outcomes the approaches detailed above have served to guide each stage of the research process and have informed researcher interaction with those taking part in the research. This research project has an added constituent in gauging the quality of the research outcome. The quality of the research question, design, data produced and final screening tool generated will be reflected in efficacy of the tool to identify decrements in driving for individuals diagnosed with a dementia. The driver screening tool will be evaluated in a further study, designed to quantify the level of agreement of outcomes between the screening tool and driving assessment performance. Therefore, although the utility of the screening tool will not provide a direct indication of the quality of the research process, it will offer an indication whether the choice of the

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approach adopted and quality of the data gathered to construct the screening tool is useful as a determinant to driving safety.

3.5 Chapter Summary:

This chapter has provided theoretical justification for the approach employed in the study.

It explains that the approach was selected to elicit research data largely ignored by previous studies but considered to be of potentially high value in providing an indication of functional performance. Research aims required a participatory role for those taking part and as such, extensive consideration of the issue of power in relation to the researcher, those taking part and the relevant discourses surrounding older age and mental health was given. The chapter examined the approaches and degrees of participation in health care research within a context of power discourses and described the approach taken. It also described the manner in which quality and trustworthiness of research would be monitored and maintained throughout the research process. The following chapter will present a detailed account of the research methods employed in conducting this study.

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Chapter Introduction:

Chapter four will present the project design and a description of the methods used to complete the study. It will provide a detailed explanation of the research choices and practical decisions made within the context of the methodological discussion of the previous chapter. The chapter will initially state the research aim and the means by which these objectives were met. Difficulties and dilemmas encountered in relation to the research design and the people involved in the research will be explored and an account of the means by which these challenges were addressed will be made clear. Next, an account of the data collection methods and a description of the data analysis processes employed will be provided. The chapter will conclude with an examination of the broad and specific ethical issues associated with conducting research with people with a condition likely to impair capacity and consent to participate.

4.1 The Study Aims and Objectives:

The primary aim of the research project was to develop a prototype screening tool for use in predicting the safety of drivers with a diagnosis of dementia. This aim was necessarily broad to enable, as part of a participatory approach, those involved in the process to influence and shape the focus of the research. Similarly, the research objectives needed to be constructed in such a way as to provide space for groups to participate in a meaningful way but also to ensure that I retain sufficient design ownership to satisfy the requirements of academic evaluation.

The objectives of the study were as follows:

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- To identify community based dementia support groups and health professional dementia special interest groups prepared to participate in the development of a driver screening tool.
- To explore the relationship of decrements in activities of daily living performance and a deterioration in driving safety.
- To utilise the group's expertise and experiences informing the development of the driver screening tool.

4.2 Research Method:

This sections provides details of the manner in which the research was conducted and the activities undertaken in meeting the aims of the research project.

Identifying Research Groups

Group members recruited for inclusion in the study were done so purposively from existing community dementia support groups and from a health professional special interest group. The sampling strategy used may be described as homogenous sampling because the research was targeted towards the focused topic of driving and dementia and required group members to have personal experience of these issues. Justification for the approach to sampling was that the research sought to examine the experience of people with dementia, their carers and health professional groups involved in dementia care and was not primarily concerned with representativeness to the wider population (Patton, 1990; Seale, 2005). These groups are also usually small in size, have significant relationship to the topic and are a valuable, rich source of data for the purpose of the study. Groups with

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the requisite experience are however few in number and relatively difficult to access owing to the possible vulnerability of group members.

Inclusion/Exclusion criteria

The use of inclusion/exclusion criteria was clearly essential for the protection of those taking part and for the integrity of the study. However the assumption that people with a diagnosis of dementia are unable to participate in research serves to reinforce stereotypes of incapacity and denies individuals of the opportunity to contribute meaningfully to research (Slaughter et al, 2007). The inclusion and exclusion criteria for the study were as follows;

Inclusion Criteria

- Health professionals with clinical experience of dementia, carers or individuals with an early diagnosis of dementia
- Experience or interest in the issue of driving
- Membership of existing special interest or dementia support group
- No significant communication deficits
- Comfortable in group setting
- Prepared to contribute to group discussions

Exclusion Criteria

Individuals who will be excluded from the study include those:

- Unable to provide valid consent to participate
- Have no experience or interest of driving either as a driver or passenger
- With significant communication deficits

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- Uncomfortable in group settings

Making Contact with Participant Groups

Volunteer Support Group - VSG

Contact with the group coordinators of two regional dementia support groups was made via email and a brief explanation of the study aims and research approach given. Initially, no response to the emails was received and a second email was sent. Both co-ordinators responded to this second email. Contact with both the group co-ordinators via telephone was then made in which a brief description of the research project was given. It was stated that owing to the small size of the study I would only require the participation of one of the dementia support groups. A meeting was arranged with the first dementia support group to respond, at which an invitation to informally present the research proposal and discuss the project with the group co-ordinator and volunteer staff was offered. The second support group agreed to maintain contact should the first group be unable to participate. The dementia support group, from which the research group was formed, comprise people with a diagnosis of dementia and carers of people with a dementia. This group meets twice weekly and has a core membership of active and committed members. The group is organised by a coordinator and three permanent volunteer support staff all of who have experience of caring for a person with dementia. The group's function is to provide information and support for people with dementia. It also has an important role in providing a supportive environment for carers of people with dementia. During the initial meeting, an outline of the study and the study aims was presented and informal discussions in which questions regarding the purpose, the intended process and strategies for dealing with distressed group members was posed by the group volunteers. Written information

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was provided (Appendix C) detailing the purpose, method and duration of the study. The group coordinator and volunteer staff served as gatekeepers to the group, vetting contact with group members. They stated that they would discuss the research project with the dementia support group members and would then contact me with a decision of whether group members were willing to take part in the project.

The dementia support group coordinator explained that the group had been involved in a number of research projects previously, but found this to have been a largely negative experience. Group members had found that researchers had lacked what was described as ‘a personal engagement with group members or volunteer staff’. The group coordinator and volunteer staff considered safe-guarding group members from what was perceived to be exploitative research practices as a key part of their current role. The coordinator explained that this project was given further consideration because of the topic area, approach to the research and telephone discussions. The research group derived from the dementia support group is referred to in the research as the volunteer support group, VSG.

Health Professional Special Interests Group - SIG

Contact with a team member of local community psychiatric nursing staff who was also a member of the North West dementia forum special interest group was made via telephone and email. From this contact, an invitation to attend the dementia forum special interest group and present the research proposal to special interest group members was accepted. This group comprises members from community psychiatric nursing and occupational therapy professional backgrounds with nurses being in the majority. Members are taken from a variety of locations throughout the Northwest of England region. Membership of the group is entirely voluntary and members meet on a monthly to quarterly basis. A

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project information sheet was provided (Appendix C) and agreement to participate in the research project was obtained from group members following this initial presentation. A group moderator was requested and the group member who had acted as the point of contact accepted this role. Again the role of the group moderator was proposed to assist with the group functioning and participate in a debriefing session which was recorded using research field notes. The research group derived from the health professional special interest group is referred to in the research as the special interest group, SIG.

The Demographic of the Research Groups

The dementia support group, from which the VSG was formed, comprised people with a diagnosis of dementia and family members of people with a dementia. The VSG had a membership of twelve persons. It comprised two people with a diagnosis of dementia and ten people who were carers of people with a dementia. Ten members were female and two male. Nine of the members were aged between 50 and 80 years. Of the group, the two people diagnosed with dementia and all the people related to the carers, had ceased driving owing to concerns of driving safety.

The SIG comprised eight members. Six of the members were nursing staff with two further members being occupational therapists. All of the group members were employed in dementia care in the clinic and/or domiciliary setting. The group was largely female with two members of the group being male. Members had a range of experience of working with all except one member having more than five years experience of working as a clinician in dementia care. Tables detailing the demographics of the research groups are included in the appendix section (Appendix D).

Setting for the Research Groups

For each of the groups, it was considered important that the meetings take place at venues usually used by the particular groups. This was useful in ensuring group members comfort and familiarity with the building's location and facilities. Meetings with the dementia forum special interest group were held in a hotel conference room used regularly by the group and meetings with the dementia support group were held in council owned property, leased by the dementia support group. Convening meetings at the groups' own settings was expected to be beneficial, especially for the development of the dementia support group, as was likely to facilitate greater cohesion, earlier in the group process. It was also found to be useful inasmuch as group members had established methods of transportation to and from the venue and did not require members to take time to find transport links to a new venue. Meetings held in the groups' own settings afforded members a degree of power when interacting with me, as I received significant assistance from the group members with geographical orientation and also with the use of the building's facilities such as obtaining a hot drink and operating computer terminals.

Introductory Group Meetings

At the initial meetings of both groups, an introduction to the topic and an explanation of the research aim of creating a driver screening tool was provided. The roles of group members, researcher and moderator were outlined. It was agreed that basic group rules would be decided and agreed by all group members and communicated at a subsequent meeting verbally and in written form (Appendix E). An overview of current driving evaluation procedures and testing tools was given and the value of the input and experience of the group members explained. A description, in appropriately adapted terminology, of how the data generated inductively from group discussions would serve to form the basis of each

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subsequent group meeting was given. It was stated that group talk would be used to generate themes and categories that would then go on to form the basis of subsequent group meetings and that each meeting would begin by reviewing the previous meeting. Members of both groups would then decide whether this was an accurate account of discussions and include or remove items as agreed by the group. An agenda of discussion themes/categories generated from the previous meetings would form the basis of the development of subsequent group discussions. This process would enable group members absent from previous meeting to be included in the process while providing an overview and reminder of progress for all group members. It was estimated that between 3 and 6 group meetings would be necessary but that this could be negotiated by the group. It was also explained that attendance at all the meetings was not expected of group members and members could re-join the group if agreed by the group. On concluding these introductory meetings, project information sheets and consent forms were issued. Individuals were encouraged to read the information and make contact, either via email or telephone, if further information or clarification was required. Group moderators agreed to collect all consent forms after a period of no less than 24 hours.

Timeline of the Project

Owing to the project being part of a University Professional Doctorate, the time in which the study could be completed was determined by the course requirements. The meetings with the groups involved in the research were governed by the established pattern of each group. This was especially difficult in the case of the SIG who timetabled quarterly meetings. Difficulties meeting with the health professional group were further compounded by the group losing

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funding to continue running the groups during the research project. The timeline of the research project is detailed in the appendix section (Appendix F).

Bringing the Research Group Meetings to an End

The VSG members were given copies of the final tool at the conclusion of the group meetings. I also provided my contact details. The VSG contacted me and invited me to attend a final meeting which was combined with a Christmas party. This final meeting not only offered the opportunity to collect data but also provided a moment of closure to the research group meetings.

The SIG meetings ended prematurely owing to the meeting venue no longer being available and subsequently the breakup of the SIG. Further group meetings could not be arranged. Copies of the final tool were emailed to each of the SIG members. Continued contact with a number of the members of the group was maintained but in relation to driving assessment services only. No further data was obtained from these members outside the setting of the group meetings.

4.3 Ethical Component:

In keeping with the participatory nature of the method and in taking account of the concerns relating to power, stereotyping and the influence of the medical approaches the research project was located outside of the NHS. The research did not involve intrusive procedures with individuals who lack the capacity to provide consent and did not require access to or the processing of confidential health records outside the group. NHS National Research Ethics Service approval was not required as both groups involved in the research

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had not been identified from services for which the UK Health Departments are directly responsible (NRES, 2011). The dementia forum special interest group is a voluntary group and is not organised or funded by departments of the NHS and the dementia support group is a charitable organisation that is organised and operated outside formal health care institutional influence. Because the research was carried out as part of the fulfilment of an educational course however, the ethical approval of the University of Salford Ethics Committee was obtained (Appendix G).

The research project was constructed to include ethical practice and review procedures designed to maintain the integrity of the research and consistent ethical treatment of individuals taking part. It was recognised early in the study design that studies may encounter ethical dilemmas during the course of the research for which simple solutions may not exist. This is particularly true of studies where control of the course of the research is uncertain and is negotiated and mapped by those taking part. These difficulties are frequently unforeseen and have not been anticipated or addressed by research ethics committees (Long and Fallon, 2007). Under these circumstances it is essential that the researcher be sensitive to potential threats to the individuals taking part for the duration of the study. In anticipating this, I have followed the ethical principles as documented by the British Psychological Society (British Psychological Society 2004) and the Code of Ethics for practising occupational therapists (College of Occupational Therapists, 2012). The ethical element of this study extended well beyond the issue of valid and informed consent and capacity and required consideration prior to the commencement of the research, during the active phase of the study and at the conclusion of the project. The dimensions of the ethical component require further detailed examination.

Capacity and Consent

Guidance recommends that individuals unable to provide full informed consent must only be considered for inclusion if the research could not be carried out successfully if it were confined only to those having the capacity to consent (Alzheimer's Society, 2010). There is however a danger that research conducted with people with a dementia can be considered too difficult to construct and negotiate ethically. This is particularly true when individuals with dementia are active participants in the research. This view, although perhaps motivated by concern about potential exploitative research practices, can be unhelpful for individuals who wish to take part in research and the field of dementia research which may give a voice to the growing number of individuals diagnosed with dementia. A growing debate regarding how best to obtain satisfactory consent to participate in research has called for more inclusionary ethical consent processes (Wilkinson, 2002). In response to this, the procedure of obtaining consent was constructed to be ongoing throughout the course of the group meetings and responsive to any changes in participants. Owing to the wide variation in level of functioning, individuals lacking capacity to provide full informed consent were excluded from the project. The capacity to consent to participation in the study was assessed using the Evaluation to Sign an Informed Consent Document for Research (Appendix H). Consent to participate in the study was recorded by group members completing a consent form (Appendix I). Consideration was given to using visual or pictorial consent forms but these were unnecessary for the individual members of the research group. Project information sheets were supplemented by a power point presentation and an informal discussion about the project. The information sheets and consent forms were written in accessible language and these were vetted and agreed by the group moderator prior to use. Discussions with individual group members at each group

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meeting were used to assess consent and also to evaluate the person's capacity to consent to their continued participation.

Confidentiality

The confidentiality and the anonymity of those involved in both the VSG and the SIG were maintained throughout the study and will continue to be in the dissemination of the research findings and further work relating to the final draft of the screening tool. The agreement to the principles of confidentiality was discussed and agreed by all group members. The VSG's priorities for confidentiality were extremely strong and centred on discussion topics not being shared with the wider dementia support group. It was made clear that confidentiality of group talk was vital for members continued participation. Group members attending as a carer explained that this was because, for their family members, the loss of driving entitlement had been an extremely painful experience and discussions relating to driving reignited and repeated the distress and anguish for them. Therefore discussion relating to the topic of driving was never discussed outside the meeting room.

The group also agreed that identities of group members would not be shared outside of the group setting. It was explained that all audio and written data obtained during the research process would be stored securely on password protected computers and in locked filing cabinets and would be securely kept for a period of no less than three years (Medical Research Council, 2012) to enable access to the data to provide source material for further publications and research projects. Audio recordings contained only first names of group members and these were replaced with numerical identifiers on the transcriptions. The

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need to breach confidentiality was discussed and it was explained that this would only be done so in the event of prevention of harm to the individual or the wider public.

The issue of confidentiality was discussed with the SIG. This group had established informal norms and rules that reflected the professional background of the group members. Confidentiality of information discussed in the group was agreed and largely assumed by all members. Group members explained that they were relatively unconcerned regarding their identities being associated with the group, but agreed that information discussed relating to the development of the screening tools within the group setting should be kept confidential.

Contingency Planning

In preparation for group members being unable to participate in discussions, session plans were formulated prior to each meeting. These drew upon talk from previous meetings and from elements of the research topic taken from the body of literature. Plans were sufficiently detailed to provide a full structure to the meeting should this have been necessary. Structured session plans were created for the event of failing discussion or poor group member input. Grand tour questions, prompts and probes were drafted for use during group meetings. These were constructed using data from previous meetings but were considered a tool of last resort owing to the need to allow discussions to occur naturally. Predetermined prompts and probes were rarely used as the group discussions were active and unstructured.

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Contingencies were agreed prior to the commencement of the meetings with the moderator of the VSG to manage events such as members becoming distressed or unwell during meetings. Arrangements included halting the meeting to address the situation and if necessary, the moderator to leave the meeting with the group member.

Benefits of Participation

It was made explicit to both research groups that there was to be no direct material benefits of taking part in the research. During meetings, members of both groups stated that they hoped to increase their understanding of the issues relating to driving and dementia and enable them to provide information to others. This corresponds well with the stated benefits of taking part participatory research which intends to provide those taking part the opportunity to reflect upon their own situation, contribute to planning actions, participate in acts, and observe and reflect upon their impacts providing an active influence upon events, in this case the designing of the screening tool.

The issue of commercial value of the tool is uncertain and was discussed with the groups involved. It is accepted that intellectual property of the product of the research project is unclear at this stage. It was agreed with both participant groups however that in the spirit of the participatory nature of the research project that, if possible, any commercial benefits be distributed among the groups involved in the study.

4.4 Data Collection and Analysis:

The use of data within the action research process is primarily concerned with learning and with facilitating active change. The data in the project therefore were used not only to build a picture of the experience of those taking part in the study

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but also acted as a tool through which the groups would evolve and refine ideas that would form the basis of the screening tool. In order to capture, develop and utilise the groups' interactions, elements of grounded theory were employed. Analysis of the data followed the constant comparative method as proposed by Glaser and Strauss (1967) and also Strauss and Corbin (1990). The model for the analysis initially looked to Grounded Theory as originally described by Glaser and Strauss (1967) but this has been subject to adaptation and significant debate. Variants of Grounded Theory and particularly in relation to the analysis of data have attracted criticism from a variety of sources such as Melia (1996) and from Glaser himself (1992) who suggests that Strauss and Corbin's approach to data analysis was overly rigid and prescriptive. In response, Strauss and Corbin acknowledge that all participants in the research act to construct the theory and that reality cannot be fully known, but that it is also constructed and influenced by historical and social factors. This development of their position and explanation of the approach to data analysis ensures that the constant comparative method of data analysis is entirely in keeping with the constructionist position adopted in the research (Cooney, 2010).

In qualitative research the processes of data collection and data analysis are far less distinct and tend to occur together (Coffey and Atkinson, 1996). This is also true of grounded theory and particularly in constant comparison. The phases of collection and analysis are non-linear, and overlap, frequently moving back and forth. The collection and the analysis of the data occurred concurrently, enabling an iterative research process and development of emergent themes. For the purpose of describing the processes however the data collection and data analysis procedures have been separated and examined as distinct processes.

Data Collection Procedure

The collection of data needs to be considered in the context of social construction and the critical perspectives. Group interviews were not viewed as a means for the producing and extracting verbal data from participants but rather were regarded as a means of capturing group product. Consideration was given to the personal, environmental, temporal, historical, cultural and power elements involved in the interactions and group product. Groups were made aware that the purpose of the group meetings was initially to look towards collaboratively constructing a screening tool; however it was made clear that the groups would be encouraged to negotiate the aims and management of the group sessions. Guidance regarding discussion content was not given or required during group meetings and discussion occurred spontaneously.

Preparation for the first meetings with each group included a personal introduction, an explanation of the aims of the research and an explanation of the role of the groups in the research as detailed earlier. Grand tour questions were formulated as part of the introductory meetings and as a contingency for faltering discussion or dialogue moving off topic for long periods, during the first meeting of each group. Grand tour questions and probes were later constructed from material generated from previous meetings but were, to a large extent, not required as discussions and interaction occurred freely and spontaneously and remained focussed on the topic in each group meeting.

For each of the group meetings a digital voice recorder (Olympus VN-8500PC) was used, with the agreement of all group members, to record the group discussions.

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Recordings were commenced immediately all group members were seated and ended when the group members moved to leave the meeting room. This was considered to be an appropriate approach in that it minimised my influence in controlling what should be recorded from group discussion by deciding when to start and stop the recordings. Discussions occurring prior to or following the meetings between group members were not recorded. Themes contained in these opening, unrecorded, discussions were frequently raised and recorded later in the group meeting or were addressed through the writing of memos. Interruption to the group meetings were recorded and included in the transcriptions.

Although the research method employed did not strictly adhere to grounded theory principles, one of the key components of the data analysis process was considered to be memo writing. The use of memo writing not only prompted analysis early in the research process but acted as a useful record of naturally occurring analysis taking part within each of the groups. Memos were recorded in a notebook and on post-it notes and provided a means of recording my own reflexive accounts and discoveries relating to codes, categories and their importance and connectedness as the research project progressed. Strauss and Corbin (1998) proposed that memos should be structured to aid the researcher's development of theory and suggested categories of code notes, theoretical notes and operational notes. This approach was discounted as the use of external categorisation was considered overly restrictive rather than offering a helpful framework. The memoing strategy used in this study was therefore free of structural constraints as proposed by Charmaz (2011). The use of this memo style permitted me freedom to focus entirely on the content of the memo.

Analysing and Developing the Data

The strategy for the analysis and organisation the data used the constant comparative method as described by Glaser and Strauss (1967) which follows a four stage process. This process comprises comparing the incidents applicable to each category, integrating categories and their properties, defining the theory and writing the theory. This process of theory development was considered to be pertinent and well suited to this research project in utilising the experience of the members of the research groups in the development of the final screening tool. The initial task undertaken was to gather together data from the written transcripts that shared an aspect of commonality and arrange them into categories. Field notes and memos were also used to feed into this process. These categories were then explored for their connections and relationships and formed into larger properties. Analysis of the data took place as quickly as practicable following all the meetings. This was essential as the meetings often took place on a weekly basis requiring the data to be transcribed and analysed in readiness for subsequent meetings. It also provided a fresher recollection of the group's discussions when organising the data. Before the process of data analysis could take place it was important to identify what would be considered to be data within the study. Grounded theorists maintain that "all is data" (Glaser, 2004). Data may be obtained from a variety sources and it is dependent upon the researcher to capture and assimilate this in order to construct theory. Because this study intended that the screening tool be constructed from and by the groups involved in the project, it was decided that data would not be included that were taken from sources outside the group setting. It was also concluded that in order for the collection and analysis of the research data to be manageable for a single researcher in the short period of time available between

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group meetings, data sources would be limited to audio records and field notes taken by myself during the meetings.

Development and Construction of the Screening Tool

The analysis of the data was guided by the processes as described by Glaser and Strauss (1967) and by Charmaz (2012, 2011). Data were transcribed from the audio recordings as soon as practicable, usually with 48 hours of the meeting. This ensured that recollections were fresh and assisted in interpreting sections of poor quality audio recordings or benefitted from contextual interpretation during the playback of the recordings. Transcription was carried out by myself and formed part of the process of data analysis. To ensure accuracy of the transcription and conveyance of meaning, audio recordings were replayed on completing the transcription process and amendments made where required. The act of manually transcribing the data and ensuring accuracy engendered a deep familiarity with the content and context while naturally facilitating the analysis of the data.

Comparing Experiences: Coding of Data

Open coding is the process whereby data is analysed and categorised for its properties and dimensions. The process used in this study followed that adapted by Charmaz (2011) who proposed that in order to stay close to the spirit of the data, coding should initially be a swift, open analysis of the data. To this end, coding took place immediately after transcription of the audio file. First level coding involved quickly reading through the transcribed data and creating codes that immediately emerged. This initial coding process gave broad and occasionally fresh perspectives on the data. Charmaz (2011) explains that this process provides a great

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deal of freedom when dealing with the data and also yielded immediate results, a practice that was important and welcome to me as a novice researcher. An example of an immediate emergence of themes from both the VSG and SIG groups was “lack of reliable information” regarding driving with dementia. This was a broad theme present in both groups. A second process of line by line coding was then conducted in order to extract codes that may have been overlooked or contained within broader themes. Examples of this second process of coding included themes such as “powerlessness,” “control,” and “conflict”.

Data codes were recorded as brief sentences on small colour coded post-it notes. An example of this relating to control from the VSG was “why state that they [people with dementia] are in control when they are clearly not.” The colour or shape of the post-it note was changed for each group meeting and transcript page numbers were also indicated on the post-it notes. This was done as to enable codes to be traced back to the group meeting from which it originated. Wording used in this coding was those used by group members as much as possible. This was done to reflect as closely as possible the meanings of the codes and also because wording I had used in the groups had been challenged by members of the volunteer support group. Interpreting language used by the group members risked altering the meaning but also served to diminish its value in communicating the message. In order to try to stay close to the data by preserving the clarity of the groups’ experience, coding using gerunds to guide coding was also used (Charmaz, 2012). Gerunds refer to the non-finite verb of sentences providing an indication of the active process involved in events. These were considered to be key words signifying actions or activity that would then be coded. The use of gerunds in the coding of the data was entirely in

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keeping with the central principle of the research in acknowledging the importance the group member actions in the progress of the research and subsequent development of screening tool, but also provided an uncomplicated practical aid to assist with the analysis of a large amount of data. At the end of each coding session, codes were placed on a large section of plain paper secured to a wall to help build a visual image of the codes and their interactions (Appendix J).

Integrating the Categories: Axial Coding

After completing the line by line coding of the data, axial coding was used to extract recurrent and important elements of the data. The use of axial coding was chosen as opposed to selective coding because the analysis was not undertaken with the aim of producing a single core category but was intended to yield a number of relevant categories. The need to adopt axial coding to analyse the data became apparent during the early stages of the data collection process when the discussions revealed that the creation of a screening tool was only part of the group's concerns and interest. I concluded therefore that in an effort to enable the data to lead and inform the analysis, that axial coding would be the most suitable approach to take. An example of the axial coding process is the development of the data from the meetings with both groups. Open codes relating to 'continuing driving after diagnosis,' 'painful uncertainty,' 'passive observer,' 'family concerns' and 'worries of replacing driving' were instrumental in developing the axial code of 'planning for the future'. This code was further developed by both groups and features as a section heading in the information pack. This process was employed to re-assemble the data fragmented by open coding, distilling and moving the content to reflect the experience of the groups. The choice of approach to the analysis of the

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data was therefore not a planned decision but, in fact, emerged as a response to the group interactions, needs and discussions.

During the coding of the data, every effort was made to allow the data to be expressed rather than confirming preconceived categories that I may have held, either through my own professional experiences or those contained within the literature. These are addressed more fully in the reflective chapter of the thesis. Charmaz (2011) explains that researchers adopting a grounded theory approach to data analysis should achieve an intimate familiarity with the studied phenomenon, but that this intimate knowledge should penetrate the existing experience of those who contend with the phenomenon. Important in this aim was the use of reflexivity. Influences and preconceptions relating to my own beliefs in relation to my professional involvement with driving with dementia, class, race, gender and age were carefully considered when coding the data in an attempt to reduce their influence their influence upon the analysis. Each emergent code was therefore examined and judged to establish whether its inclusion could be legitimately justified as originating through the data or whether the code developed from other sources.

Clustering

Clustering was an on-going process for the duration of the research project that took place on a dedicated “thoughts wall” (Appendix J). Clustering as explained by Charmaz (2011) provides a non linear, diagrammatic means of visualising and organising the data and exploring how the data may link together or act in opposition. Charmaz explains that one of the main objectives of clustering is to

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liberate one's own creativity and move away from more linear processes.

Clustering provides an opportunity to view how elements of the topic interlink and also enables changes to be made easily as the process progresses. This was instrumental in the process of axial coding. The method of clustering used in this research project involved taking the codes generated from the open and axial coding of the data and grouping those with a close connection together to form a larger collection or nuclei. This promoted a further examination of the axial coding that tested the robustness of the codes. These groupings then produced Dendron-like arms that reached to form connections with other codes. From these connections, links were explored and the strength of connectivity established. Connections also lead to subsequent codes being generated. The process of transforming data from the spoken word to an audio recording into text and then onto a diagrammatic form fed naturally into the creation of the draft publication. Indeed, the final version of the cluster diagram provided an invaluable blueprint for the structure and content of the screening tool and information leaflet.

The use of clustering was entirely in keeping with the spirit of the study, drawing upon a creative approach towards dealing with the research material. The process enabled a visual planning and organising of a large amount of data while also allowing experimentation in the manner in which the codes related and fit with one another. It welcomed chaos but provided a means of obtaining clarity from that chaos.

Defining the Theory: Constant Comparison

Glaser and Strauss (1967) and later Strauss and Corbin (1998) propose comparative analysis as one of the essential features of the grounded theory approach. The purpose of the constant comparison carried out during the research project was to identify, in collaboration with the group members, patterns in the words used that recreate and communicate the constructions of group members experience. This was then used as a framework on which the screening tool could be based.

Throughout the research, constant comparison was used to compare elements of data to one another to test similarities and differences in order to provide an understanding of their relationships and facilitate a conceptualisation of phenomena. Sequential comparisons were made, these being of data generated during different meetings and by different groups. The process of analysis necessarily lead to interpretation of the data and this was considered a natural element of the analysis process and was made explicit when exploring the emergent concepts further with the groups. These emergent concepts were then explored in terms of their potential value by the groups and developed further or discarded. The concepts were refined and finally integrated into a final framework that formed the basis of the information booklet and screening tool (figure 3).

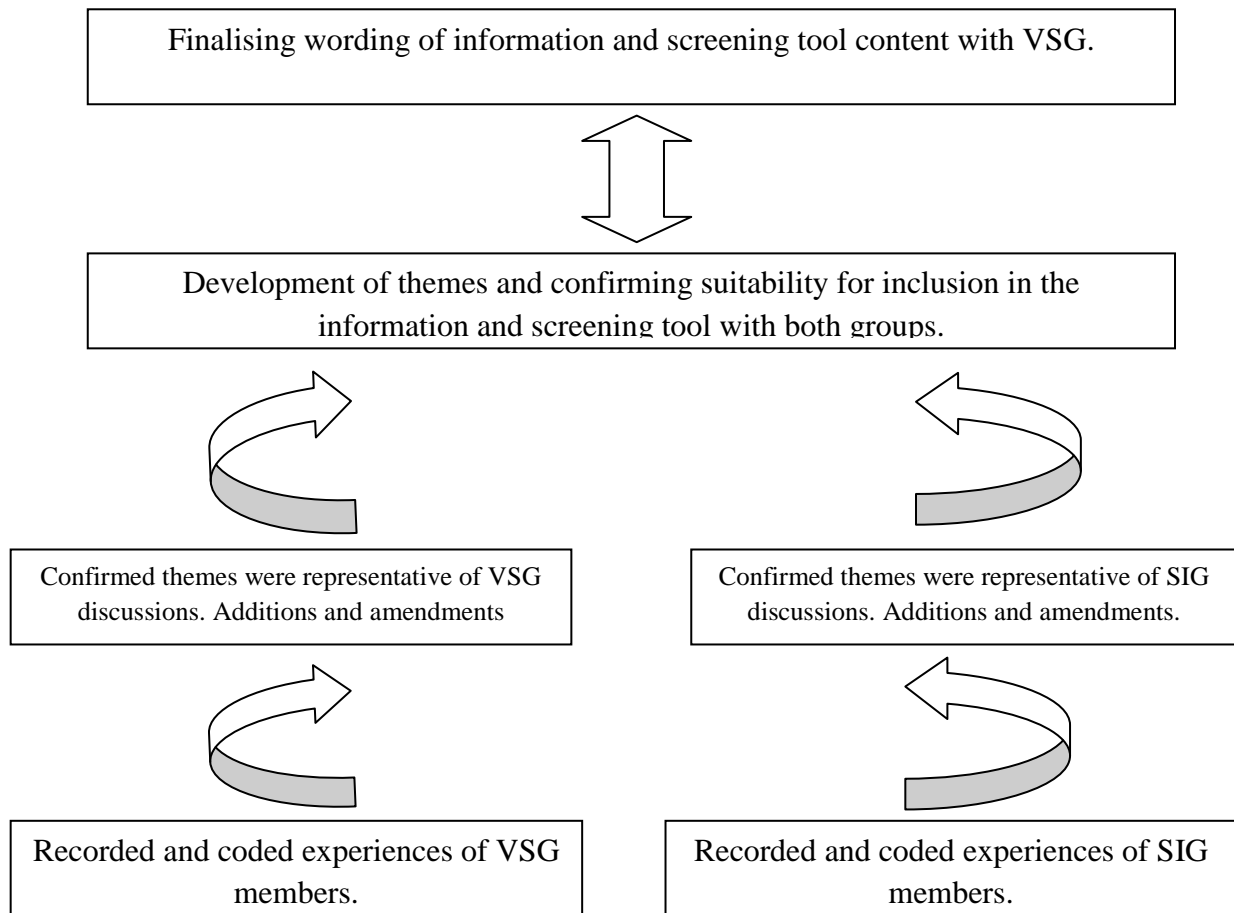


Figure 3

4.5 Chapter Summary:

This chapter has provided an overview of the purpose, approaches taken to data collection and to data analysis. It has described the manner in which experiences were explored and recorded in the group meetings and then further developed by the research groups to form the basis of the final tool. The manner in which the analysis process enabled the research to respond to the experiences of the research groups taking part was provided. It also explained that adopting a flexible and non-linear approach to the data collection and analysis was vital to the integrity of the research and to the data produced. Finally, the chapter outlined the ethical considerations of the research, with a particular focus upon the elements of capacity

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and consent in dementia research. The following two chapters of the thesis will describe and discuss in detail findings of the group meetings.

Chapter Five: Findings and Discussion: Emergence and Development of the Information Section:

Chapter Five: Findings and Discussion: Emergence and Development of the Information Section:

Chapter Introduction:

Chapter one and two of the thesis introduced the reader to the theoretical background of dementia and the affects upon driving. Chapters three and four discussed the methodological considerations and the research design employed to conduct the research. Chapters five and six are concerned with the findings of the research and will be structured according to the development of the tool. Although a proportion of the findings were used to develop both sections of the final tool (Appendix K), chapter five will broadly address issues relating to the information section of the tool and chapter six, the screening tool element. Each of the themes described is immediately followed by a short discussion of the elements addressed. This approach was used to enable the reader to remain close to the process of the development of the tool while providing the reader with details of the discrete elements that comprise the tool and a clear justification for their inclusion (Chenail, 1995). Language used in presenting the findings is commensurate with the group members own terminology. The term patient therefore will be used when discussing people with dementia in relation to the SIG and person with dementia at all other times.

5.1 Reviewing the Research Aim:

The primary research aim was to develop a prototype screening tool for use in predicting the safety of drivers with a diagnosis of dementia. The development of the screening tool was to be carried out through an exploration of the experiences and understandings of dementia, as constructed by the health professional and dementia volunteer support groups. It was accepted that owing to the participatory nature of the research method used this aim would need to include a degree of flexibility and responsiveness to the group's input.

Chapter Five: Findings and Discussion: Emergence and Development of the Information Section:

The aim of constructing a driver safety tool remained constant throughout the research project. The input of the research groups however shifted the emphasis from the development of the screening tool to developing awareness of the issues related to driving and dementia. The emergence of additional aims for the research developed over the period of the group meetings.

1. To develop an information pack regarding driving with dementia.
2. To consider the transition from driver to driving cessation and strategies to replace driving.

The broadening and addition of aims to the research project was a dimension not anticipated prior to the commencement of the study. The research approach was selected however, to accommodate the input from those involved in the research and enabled it to be responsive to the wishes of the groups.

5.2 Information for Drivers with Dementia:

During the first meetings both research groups were unclear about the effect that a diagnosis of dementia had upon an individual's driving and requested information relating to the legislative requirements of the driver and the clinicians involved in their care.

Members of both groups described deficiencies in the information received from agencies and a lack of guidance from health professionals in meeting the licensing requirements.

The coordinator of the VSG also reported that the health professionals involved in the care of people with dementia were often uncertain about licensing requirements and about issues relating to driving.

I attend a group with the community psychiatric nurses and they have exactly the same kind of worries and feelings about it. They say they don't know about the

Chapter Five: Findings and Discussion: Emergence and Development of the Information Section:

information from the DVLA. The DVLA are quite vague about what they need... and I think that the consultants are very much in the same vein. There is a little bit of, I don't know what to do about this, it is right at the periphery of the consultants concern. *Brenda. VSG Meeting 2, 449 - 456.*

The experiences of the members of the research group suggest there is an uncertainty and confusion regarding the responsibilities of the licence holder to inform the licensing agency of their medical condition. A number of members of the VSG had failed to inform the DVLA of the condition and believed that this would be done by the health professionals involved in their care.

Cath, a CPN member of the SIG explained that driving was one of the many areas routinely addressed during an initial contact with a person newly diagnosed with dementia on their first contact with their services.

And they always check don't they once they've had diagnosis. It's always 'have you informed the DVLA' or the person's family or whatever. *Cath. SIG Meeting 1, 389 - 391.*

Donna, a fellow CPN member of the SIG discussed her practice in ensuring that the person had informed the DVLA but expressed concerns regarding the DVLA reporting process and whether the advice and amount of time they were able to dedicate to the monitoring of driving was sufficient.

And again, we always do that [enquire whether the person diagnosed with dementia has informed the DVLA of their condition], to see that that's done anyway legally, and I don't know really after that. It's usually about six months then really before we're seeing that person. Obviously, if there's no concerns in between, then six months is quite a long time isn't it in between for them to be seen again. *Donna. SIG Meeting 1, 394 - 399.*

Chapter Five: Findings and Discussion: Emergence and Development of the Information Section:

In contrast, other group members explained that advice and monitoring of driving was not a core area of concern for clinicians and was not consistently addressed by all health professionals as part of their care or treatment. The level of accuracy and detail of information that was given to people relating to driving by health professionals tended to be dependent upon the time available, perceived value and level of knowledge of the individual practitioner.

I suppose the other thing is how would you incorporate [driving] into your code of practice? I remember someone saying well you know I'm fine; people are time pressured and stuff. You see it depends. Different clinicians are aware of driving.
Rebecca. SIG Meeting 2, 14-20.

The VSG and SIG agreed that although the development of a screening tool was necessary, a more pressing need from their own experience was an information resource providing accessible and reliable information about driving after a diagnosis of dementia.

A screening tool is useful, but I think probably what it needs to be is something else as well. I think it needs to be an information pack, or a tool kit about the issue of driving. I think lots of people said last week, we are not sure what the procedures are, what the process is when we first received the diagnosis of dementia and what we are meant to do with regards to driving. *Brenda. VSG meeting 2, 74 -80.*

Implications for the Information Pack: Discussion

A large proportion of the VSG had failed to inform the DVLA of their medical condition, believing it to be the responsibility of their doctor or had not considered the need at all. Most of the members of the VSG agreed that information and guidance regarding the process of reporting a medical condition had not been received by or could not be recalled by group members. Reasons for this were felt to be that during the initial contacts with the patient, a number of more pressing issues for the health professional needed to be

Chapter Five: Findings and Discussion: Emergence and Development of the Information Section:

addressed, such as the commencement of medication and the establishment of a cognitive base line. The members of the SIG were candid about their lack of a full understanding of the issues related to driving. The findings of this research support previous studies that demonstrate inconsistencies and failures in the accuracy and consistency of information provided about driving to people with a diagnosis of dementia (Gillespie et al, 1999; Hawley et al, 2010). This failure to fully address the issue of driving contrast markedly to the concerns expressed by the health professionals later in the person's disease process when unease about driving safety gathers greater importance. Members of both research groups emphasised the need for information provision at the point of diagnosis for the person diagnosed with dementia, their family members and the health professionals providing care and were keen that information provision be a central feature of the final tool.

5.3 The Social Construct of Driving with Dementia:

The members of both groups recommended that accurate and sufficiently detailed information was essential in providing guidance for the driver whilst also being potentially useful for family members and spouses. The role of information given at an early stage was also seen by the groups as a means of adjusting the meaning of dementia for the individual with the diagnosis and those close to them. Janice and a number of other members of the VSG felt strongly that societal attitudes towards dementia are quite often negative and focus upon loss, disability and decline of the person.

‘If we have only got negative stereotypes when you have got dementia, you can't do this you can't do that, you have got to stop driving, you can't, you know, do everything [then] why would you go and get a diagnosis?’ *Janice. VSG Meeting 2, 404- 407.*

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The group expressed dissatisfaction towards cultural perception of dementia and the manner in which this is occasionally presented. Group members explored how people with dementia and the symptoms associated with dementia were negatively represented in popular media and how they were frequently the subject of mocking humour. Marian recalled an occasion when the clinical features of dementia were replicated on a popular television programme.

It's interesting but I didn't quite like it – I was offended by it. On Top Gear, Richard Hammond, when they do stupid things, they actually hypnotised him and they put him in a car, and he didn't know how to drive. He sort of sat there and said right well, I don't know what to do. They said put the key in... What do I do next? They'd hypnotised him and I thought I didn't like it really as they were all laughing and thought it hilarious. But, if it was you and you had something wrong with you. They take it a bit far on Top Gear. But I thought; just imagine if that happened to you and it makes you think. It was really getting me stressed, really distressed, as everyone was laughing about it. I don't like this; it's a bit near the knuckle. [It was] upsetting me a bit, as this isn't fun television. If they were ever in that predicament and couldn't do it! I don't think they realise sometimes. It was silly – calling it entertainment – it was interesting but very distressing. *Marian. VSG Meeting 4, 392-399.*

The VSG made reference to the disabling effect of the label of dementia and how the condition is understood by people without direct experience of its effects. Group members felt that societal understandings of dementia were wholly negative and centred upon loss of the independent self. In this, driving constituted a significant element. The effect of negative stereotyping upon the person was also considered a problem by the members of the SIG and an issue that members felt they occasionally needed to address when forming a relationship with people newly diagnosed with dementia. Alan explained that

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representation of the driver with dementia in popular media is an important influence upon attitudes towards continued driving with dementia.

We've all heard the paper headlines about older drivers and older drivers going down the wrong side of the motorway and that sort of thing but the vast majority of people who have a new diagnosis of dementia are absolutely fine driving and I think that the amount of people that have been told they can't drive who actually you know, would be able to. *Alan. SIG Meeting 1, 248 – 252.*

The groups were eager to ensure that the negative stereotyping and common misconceptions surrounding dementia were elements that were carefully avoided in both the message and the language used in the final information component and screening tool.

Control and Empowerment

The research groups made reference to the difficulties with acceptance associated with the impact of dementia upon driving. Both groups pointed to the unexpected, enforced and distressing process of being asked to cease driving. Christine, a member of the VSG explained that the request for her husband to stop driving came suddenly and, from her perspective, brutally with little evidence to support the decision.

I mean the first time we went for the results of my husband's MRI scan the consultant comes into the waiting area and doesn't call your surname they just call and she said 'how have you got here today?' He said 'I've driven' and she said 'you've driven?' We said 'yes'. I said 'we could have walked' because we live within walking distance of the hospital and she said 'well, I'm afraid you shouldn't be driving' and he said 'how can you say that when you've only seen me once before?' *Christine. VSG Meeting 1, 65-70.*

Self determination over daily activities diminishes gradually for the person with dementia with care being taken up by close family members. The VSG members explained that

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maintaining the established relationship with family members or spouse was extremely challenging and difficulties with this grew as the level of cognitive impairment increased. A significant and early milestone in the process of changing roles was considered to be when there is a concern about a person's driving safety.

How do you know when they are not safe (pause) and how do you explain to them as they are in control when you take it away? It's a man thing... well isn't it, When you take it away from them because my husband never let me drive? I used to ask, 'Can I drive the car today?' and he wouldn't let me as he loved driving. When he had to give that up – ooh gosh. *Marian. VSG Meeting 4, 187 – 192*

The prospect of satisfactorily ceasing driving was explored by the research groups. An important element to the acceptance of driving cessation was the degree of perceived control the person had in the decision making process. Audrey described her husband's experience of being informed that he should no longer drive owing to the progression of his dementia but explained that this had not caused distress as anticipated.

When they told my husband he couldn't drive he wasn't bothered. He's been driving since he was seventeen. He was a HGV coach driver. He was a driver above thirty odd years and he hasn't batted an eye lid and I don't understand why because he used to love driving... I wonder if the difference is having the choice. If you're told you can't drive or you can't do something you want to do it more. *Audrey. VSG, Meeting 3, 457 – 462.*

Both research groups discussed the value of an active involvement from an early stage in the eventual need for the person to cease driving. The SIG members explained their experience of the significance of early collaborative planning for the management of continued driving and driving cessation.

I think that leads into what we were talking about clinical pathway, there's two issues, educative and information issue and a testing issue. I think we need to look

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at both of them. Sometimes, the person is in more control when they've gone on and done it themselves, they've got that awareness the easier for them to let go of driving rather than being told sorry you can't drive anymore. *Donna. SIG meeting 2, 146 -152.*

The two groups asserted that while active inclusion in the process of driving cessation was an important element in the acceptance of a person with dementia, a number of the VSG members also described the possible value of information and screening in aiding and relieving family members of the burden of supporting the person through the transition to driving cessation.

The screening tool you are thinking of creating it sounds like if the doctor says 'you don't have to drive anymore' without any form of assessment, that's what makes like the person upset. It's the fact that they haven't had a chance to be like screened". *Brenda. VSG meeting 1, 540 – 547.*

But at least with this kind of thing it will probably take the hassle off you because it isn't you saying 'no', it's the doctor [who] said you can't do it. *Janice. VSG meeting 1, 550 – 554.*

Implications for the Information Pack: Discussion

The change in the locus of power for the person diagnosed with dementia is a prominent theme throughout the course of the condition and central to the activity of driving. The loss of the capability and legal sanction to drive is perhaps the first and most obvious impact upon self determination resulting from dementia. Concerns expressed by others may result in the questioning of a person's ability and ultimately the forced removal of a person's entitlement to drive. Both the research groups identified that there exists a current lack of

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structured opportunity for the person with dementia to participate in decisions about the monitoring and safety of their driving. A paucity of information and practical guidance results in the person having very little awareness of the issue of driving safety and frequently little or no control in the move to cessation. The benefits for health professionals of patient awareness and involvement in the process of driving cessation were explored by both groups and are supported in the literature (Liddle, et al, 2008; Musslewhite, 2011a; Musslewhite, 2011b). Patients with an early awareness of the issues associated with driving and dementia were felt likely to be more accepting and prepared for the eventual need to cease driving. The focus of the health professional with a patient who is aware of the need to cease driving becomes one of collaborating and supporting the person through the transition of driving cessation rather, than being part of the instrumentation responsible for the removal of driving entitlement.

Structural stereotyping of dementia was a prominent theme in the findings and it was felt to be present in all sections of society. Both groups felt that dementia was nearly always seen in negative and disabling terms. Link and Phelan (2001) suggest that for stereotyping to take place, power needs to be exerted over the group in question. Members of both the SIG and the VSG groups identified the ways in which people with dementia were characterised in the popular news and media. The person with dementia is frequently depicted as being forgetful and dependent. Drivers with dementia were also depicted as a significant hazard and a danger to other road users. It was pointed out by the VSG members that people with dementia are exposed to dual stigmatisation of having dementia and also with the stigma of aging. This introduced the element of a physical frailty along with a perceived deterioration of cognitive capacity. Both groups made reference to the common stereotype of the elderly driver and the manner in which this was sustained in

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society. Members of the VSG discussed the societal discourse in relation to older people. It was suggested that older people are considered to be a cost to society rather than a productive member and therefore less worthy of a place on the overcrowded roads. This perhaps explains the common perception of older drivers that they are unwanted members of the driving community who are the subject of personal and intuitional attacks upon their driving status.

Responses to the person with dementia were considered to be inhibitory. Stereotyping of dementia influenced relationships with friends and family and also influenced the person's perceptions of themselves. Stereotyping and stigmatisation was felt to influence behaviours, attitudes and decisions of the person themselves and their family members. Evidence of the effects of stereotyping emerged in a number of ways. Group members suggested that the regulation of the frequency, duration and timing of driving and, in some circumstances, cessation of driving entirely was a direct response to fearfulness of the driver's capacity generated from wider societal discourse regarding drivers with dementia.

The inclusion of the information section was considered by both groups to be of vital importance in addressing the effects of stigmatisation, power and loss. Information regarding dementia is a key component in demystifying and normalising dementia, not least for the person newly diagnosed with dementia. This significant element of the research appears to concur with Byrne (2000) who states that the starting point of reducing stigma is a narrowing of the knowledge gap by approaches to education.

5.4 The Meaning of Driving:

Both groups discussed the importance of driving and explored the ways in which people related to the act of driving a motor vehicle. Both groups explained that driving represented more than the act of transportation. The groups reflected that the effect of driving cessation not only has the potential to interfere with vocational, domestic and leisure activities but also felt that the loss of driving entitlement included consequences for personal identity.

Identity

Both the groups felt that driving embodied something other than purely a means of transportation. Driving was considered to represent self-determination and independence within the person's social context. For the group members, differences in the relationship with motor vehicles and driving also occurred between males and females.

You are battling with male pride as well though aren't you? Well it is a macho thing isn't it being in charge? You don't get many female racing drivers. Definitely a man thing. *Janice. VSG meeting 1, 562-564.*

Driving is perceived to embody aspects of adulthood and status within wider society and therefore the consequence of removing the entitlement to drive often represents feelings of loss of status, not just the driver themselves but for those closest to the person with dementia. The impact of driving cessation was found to be profoundly important for the family members of the person within the volunteer support group. The loss of skills required for safe driving was viewed as a significant milestone in the deterioration of the person's self and their established family roles. Janice in the VSG explained that in her experience those closest to the person with dementia may have difficulty adjusting to the progression of dementia and consequent changes to the person's function and roles.

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I remember when my dad was driving. My dad had driven me all my life and I felt totally secure and safe when he was driving and it was when I noticed he was doing something stupid... It's something he wouldn't have done. He'd made a bad judgment call, but knowing it was my dad was totally devastating because my dad had been this security symbol and, you know, I felt so safe with him. *Janice. VSG meeting 2, 219 -225.*

The SIG explored similar experiences. Rebecca explained that the difficulties of family acceptance of the prospect of enforced driving cessation had on occasion manifested in refusal of services by family members.

When I rang up to review; she said 'I don't want you coming. I don't want you to come here and I don't want have anything to do with anyone at the memory clinic'. So I said 'his medication needs reviewing, so someone would have to come'. 'Well you can come but I don't know what kind of reception you are going to get' so the first thing I did when I went in there was talk about the driving. *Rebecca. SIG meeting 2, 36 – 41.*

The difficulties of acceptance for relatives and spouses were clearly illustrated by Shirley, a member of the VSG. Throughout the course of the meetings, when discussing her husband's driving, Shirley expressed widely differing emotions and attitudes towards her husband's ability to drive. The issue of driving had been central to Shirley and her husband and was especially pertinent as they had both previously worked as approved driving instructors. Her struggle with the loss of her husband's ability to drive was present throughout the group meeting process and her ambivalence evident throughout the research process and each of the group meetings.

My husband is quite capable of driving and I've got to say something, he's a better driver than I am even though I'm a driving instructor because I'm used to driving for other people, so I come to a give way for instance and I think, I still can't get it out of my head that I'm not... that I'm driving for myself. So I give a little time for

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them. I would consider him to be a better driver than me because he brakes faster.

Shirley. VSG meeting 1, 94 -103.

I know he can drive and he does drive on occasions, he is insured. The insurance is valid if anything goes wrong ... *Shirley. VSG meeting 1, 217 – 218.*

In contrast, in subsequent group meetings Shirley expressed her deep concern over his ability to drive safely on the public highway.

Donald is definitely not aware – he thinks he is very safe – he is a lot of the time but I don't let him drive because sometimes he is not safe. *Shirley. VSG meeting 4, 298- 299.*

People are diagnosed early like my husband and he can drive... but he could not drive now I wouldn't like him to, he takes it out of the garage but I don't want him going on the main road for instance. *Shirley. VSG meeting 4, 73-76.*

In the meetings, Shirley was explicit regarding the difficulties in addressing concerns regarding driving safety and how this leads to a sense of complicity in the erosion of roles and activities such as driving. Shirley described well the tension between, on the one hand, a regard for their driving safety and on the other a being a part in the deterioration of the person with dementia.

It's like the lady said, you can't take everything away from them. I've done it very in a very roundabout way with Donald because I've said 'take the car off the drive'. I've said to him 'park the car there, it's too small for me love'. I do that when there's no one around and I know there's not going to be any danger. I let him do it because it keeps him... He's still got a car key on his on his fob because if you take everything from them and you don't deal with it properly... This is why this group helps. *Shirley. VSG Meeting 2, 522 – 531.*

Loss of Role

The cessation of driving has practical implication for a person's participation in established roles and responsibilities. Although the condition of dementia is recognised as one of older age, it may also affect individuals of working age. This can have significant implications for the continuation of employment and the ability of the individual to fulfil their family and leisure roles to their satisfaction. During a SIG meeting, Cath discussed the effects of driving cessation for one of her patients and the distressing consequence to their life situation.

You've got to spend time dealing with that really because I mean we had a client who he was a driving rep and he lost his licence. I went to see him and he was really, eyes glazed over about not being able to drive. He couldn't do the spatial awareness test... He wouldn't give me the piece of paper; he was tugging [at it]. He wouldn't give it me back. He tried about three times he couldn't do it. And I saw this glaze come over his eyes because he had a caravan he went to. He had children at a distance that he used to drive to. *Cath. SIG meeting 2, 588 -596.*

Implications for the Information Pack: Discussion

Christiansen (1999) suggests that identity is closely linked to the actions, interactions and relationships with others. It informs the formulation of an understanding of self that provides coherence and narrative to everyday life events. The connection between driving and identity is strong and may be a source of the resistance towards driving cessation of those diagnosed with dementia. Culturally, the relationship with the motor vehicle is complex and extends well beyond simply the purpose of transportation (Musslewhite, 2011a). The profound sensitivity of the subject of driving and potential loss of driving entitlement was clearly expressed in this research project and runs far deeper than its practical function of a convenient mode of transportation. Our ability and entitlement to

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drive is a measure of achievement and an expression of skill mastery (Ellaway, et al, 2005). It defines us as adults and is woven into the fabric of social roles. We express our individuality and our personality through our choice of vehicle and we define our values by our driving styles (Steg, 2005). We are careful drivers, fast drivers, courteous drivers, skilful drivers and correct and accomplished drivers. Our relationship with vehicles are encouraged and shaped by the organisation and values of society (Steg, 2005; Windsor et al, 2007). An enforced revocation of a driving licence for some represents an imposed removal of a part of one's-self. Sudden and enforced changes or exclusion of roles may have a marked influence upon personal identities, self narratives and interactions. Driving for people with dementia may represent an embodiment and maintenance of the characteristics that define them as independent, active and autonomous adults and any challenges to continued driving are therefore perceived as threats to these.

The changes to the identity of the person with dementia are a difficult matter for family members to reconcile. These research findings detail family members' witnessing the decline of their spouse, parent or sibling, the loss of driving skill serves as a powerful example of the person's deteriorating capacity. Reactions to this included a prolonged mourning, a non-acceptance or avoidance and, as in Shirley's case, deep ambivalence towards her husband's driving and driving safety. In her contributions to the group, it was clear that Shirley found significant difficulties with acknowledging the loss of her husband's ability to drive. This sentiment was shared by other group members who described sudden changes in their spouse or parent resulting in them shifting from them being the source of protection to being the focus of protection. Family members also explained the profound emotional struggle of their perceived complicity in the removal of driving entitlement and the physical and emotionally disabling consequences of this. The

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acknowledgement of the importance of role maintenance and that people with dementia may continue to drive safely was a key message for the information section of the tool.

The loss of the ability to drive was particularly important for those who rely on independent vehicle use for productive engagement in activities such as paid work or formal and informal volunteering. Although the diagnosis of dementia is closely associated with older age, the incidence of early onset dementia, those people diagnosed with dementia under the age of 65 years, is possibly far greater than the current estimate of approximately 15,000 in the UK (Knapp and Prince, 2007). In addition to this, the move to raise the age at which people retire from employment is likely to result in an increase of people of working age with a diagnosis of dementia. Given that driving is frequently integral to the working role and not simply a means of commuting to the place of employment, may result in the person being unable to adequately fulfil their occupational role and lead them to change or even cease their involvement in employment. Practical planning designed to accommodate changes to driving status as soon as the diagnosis has been received may help alleviate difficulties with role fulfilment later in the disease process.

5.5 How Might Dementia Affect Driving?

Both research groups discussed the difficulties of determining normal driving behaviour and driver errors resulting from the progression of dementia. Members of both groups stated that many drivers without a medical condition were prone to making frequent and in some cases catastrophic errors. In fact, both group reported failings and occasions when they considered their own driving to be of a poor standard. Through an exploration of their

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experiences both groups were able to identify errors that were considered to be characteristic of a deterioration of the elements necessary for safe driving.

Typical Driving Behaviours

The task of discriminating between driving errors associated with dementia and those errors attributable to poor driving was addressed by both groups. The research groups felt that unsafe practices and behaviours were common in the wider population of drivers. Groups also felt that errors made, even those resulting in a collision, did not necessarily indicate that driving was unsafe. Driving errors and to some degree, vehicle collisions were considered a somewhat common and understandable element of driving. The groups were of the opinion that simply responding to errors in driving, even those that could be classified as serious, would not necessarily provide a reliable indicator to a decline in the safety of driver with dementia. Alice, during a VSG meeting expressed this feeling well.

I think that the decisions about driving and when is safe or not safe to is a really difficult one because it's not clear. You have one bang into someone's car; does that mean someone shouldn't be driving? I mean we have all done it; a lot of us have hit a car. I have done it, but does that mean I should not be driving? I think people, the general public, will be involved in bumps all the time. *Alice, VSG meeting 2, 328 – 334.*

Identifying Problems in Driving - Early Signs

The difficulties of determining errors characteristic of a decline in cognitive capacity owing to the progression of dementia were explored by both groups. Members of the SIG used their experiences of the symptoms of dementia as a base from which to examine how driving may be impaired. The VSG discussion centred upon their personal experiences of driving with dementia. During the meetings both groups discussed the elements that indicated when driving was becoming unsafe for the person with dementia.

Visuospatial Judgement

Visuospatial awareness was a significant concern for the members of both groups. Cath explained that she had not been aware that visuospatial disturbance could be a prominent feature of dementia and was now acutely sensitive to the affects that this might have upon daily function and in particular driving.

There's another group as well and there was... was it four people? And they were all talking in [sic] length about their visual-spatial[sic], and I'd never in all my years picked up the problems that they have. *Cath. SIG meeting 1, 443-445.*

Fellow members of the SIG shared their experiences of clients driving and the problems that they considered may be attributable to a visuospatial disturbance.

It's like the visual-spatial [sic] like you were saying like are they getting closer to other cars or are they getting sort of, and when they're parking are they having problems getting in a parking space now you know... reversing in, you know, those sort of things. *Donna. SIG meeting 1, 242 – 245.*

The disruption of spatial awareness was also an element that was prominent as a feature of the VSG member's experience. Both Marian and Jenny described incidents when proximity to other vehicles had been in evidence.

I think its misjudging distances and overtaking anything or parked cars and going past parked cars. I noticed he was getting too near them, you know. *Marian. VSG meeting 2, 174 -176.*

Driving with somebody with the dementia they drive too close. They don't give enough stopping distance, whereas I think we have become more cautious and we leave a good distance and a good space don't we? *Jenny. VSG meeting 2, 364 -368.*

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Deficits in visuospatial awareness may also be responsible for a failure to hold a consistent position on the road and result in the driver allowing the vehicle to drift across the carriageway. An example of poor position was described by Marian.

I was telling my sons and they said, 'Oh... he's alright isn't he?' But, we had to go to Manchester. It was just after Boxing Day. An aunty of ours was really poorly in this home and we didn't know where it was, and... He said, 'come on, we'll go and find it.' So I rang my son and said, 'do you mind coming' because he used to be brilliant. He only had to go a place once and he knew everything about it you know. So he said 'I'll come, but I'm not driving.' So I said, 'Well, sit in back then.' So he sat in back and we were going along Manchester... motorway, and he said 'Father choose a lane and stay in it!' And I thought, well he's seen it now and he knows. *Marian. VSG meeting 2, 198-210.*

Diminution in Response to Hazards

The capacity to recognise and respond to environmental cues and hazards was considered to be an important element in the ability of the person with dementia to continue to drive safely. The failure to react when confronted with conspicuous hazards was felt to be indicative of a loss of skill that rendered the driver as unsafe. The members of both groups made the distinction between a single event of failing to respond to a potential hazard and repeated episodes of the lack of a response at areas with a high level of environmental stimulus, such as signal controlled junctions and pedestrian crossings.

Well no, he didn't see why he should stop at a pelican or if it was on red or stop at a zebra. I made sure that I didn't let him drive by himself I made sure I always went and managed to stop him killing anybody. *Monica. VSG meeting 1, 415 -421.*

A consistent failure to respond to environmental cues and clear hazards such as traffic signalling was considered likely to be a significant indicator of deterioration in a person's

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awareness and driving safety. These types of errors were described by group members and their importance emphasised, because they did not represent the person's usual driving behaviour. Christine described that failing to act appropriately in response to familiar traffic situations was a significant event that indicated changes in awareness and driving safety.

I don't think it would have picked up on Tom's problem, he'd forgotten how to turn right. He was saying why they are coming when I'm supposed to be going. From about nine months before the doctor actually stopped him driving, it was an absolute nightmare. *Christine. VSG meeting 1, 409 -413.*

Reduction in Attentional Capacity

The ability to manage more than a single event is a necessary element of driving. Members of both groups discussed the role of attending successfully to multiple stimuli and emphasised that this capability was often disrupted with the progression of dementia. Reductions in a person's ability to share attention between two or more events or tasks were considered to be a significant feature in dementia. People being overwhelmed in a variety of everyday situations were described by the members of both groups. When asked to consider how this might manifest within driving a number of occurrences were described by group members. Cath during a meeting of the SIG recounted her father's reduced ability to operate the vehicle controls correctly while driving. Cath did not disclose whether her father had in fact received a diagnosis of dementia.

Cath. My Dad doesn't change gear, that's what we felt was a real problem.

Alan. It's an automatic car.

Group laughs.

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Cath. But since [then] he's got an automatic. When... he was taxi-ing us around it was like "change gear dad!" and he just seems to be completely oblivious to it. And so that was a real major concern but obviously we got him automatic now. *SIG meeting 1, 279 – 285.*

Members of both groups expressed concerns that an inability to divide attention between tasks is common for many people and therefore could not be relied upon to indicate unsafe driving. Aspects of driving behaviours that have in some way changed however were considered by the groups to be more of an indicator. Changes in driving behaviours that were attributable to divided attention such as becoming overwhelmed in more complex situations or driving excessively slowly for the traffic situation were felt to be significant. Christine described this problem in relation to her Mother's driving.

I used to drive, my mum used to take me out, or we used to share the driving, and it got to the point where, this was before she was diagnosed, that I was so frightened of getting in a car with her because she was driving so slowly, because she was so frightened of getting a speeding ticket, I really felt she was seriously unsafe on the roads. I think she was really a danger. She was really crawling about 15 miles an hour. *Christine. VSG meeting 1, 123-133.*

The experiences of group members indicated that an important feature of the effects of dementia was a reduction in the speed of the person's ability to evaluate and act accordingly. Jane described the consistent slowing of her mother's responses to situations, particularly at junctions.

No, she was alright; it was just driving very slowly. She'd come to the give way and then she'd stop and she'd stop and she'd stop and it's like but there's nothing coming. But there might be another car coming in the opposite direction, she'd just be completely bamboozled. It was just like a rabbit caught in the head lights. *Jane. VSG meeting 1, 165-168.*

Roundabouts. Roundabouts. Would you agree? It's the indecision... you know lots of people make decisions straight away. But it's like "do I do this, do I do that?" It takes a bit longer you know. *Jane. VSG meeting 3, 191 – 193.*

Deterioration in Safe Decision Making

The ability to consistently and reliably evaluate situations and act safely in all circumstances was reported to be a significant feature of peoples experience in recognising the deterioration in a person's driving safety. Group members recounted significant errors that were important in recognising when a person was becoming unsafe driving.

I noticed he was doing something stupid. We were coming down the main road and turning left and there was a car parked at the bottom of this road. He was tuning left, so he swerves right around and there was a car coming down [in the opposite direction] so he ended up on totally the wrong side of the road. And it's something he wouldn't have done; he'd made a bad judgment call. *Janice. VSG meeting 2, 212 -216.*

Although a decline in the ability to make independent decisions in situations was identified as a noticeable change in the person's driving, this reduction did not necessarily result in collision or near collision but often necessitated passengers to assist with the decision making. A number of group members described occasions when the driver's ability to make decisions had deteriorated to the extent where verbal prompting was required to ensure that the driver acted safely.

And now it's a little roundabout and me going 'go-on, go-on' and me saying 'Bob, you've got right of way!' *Monica. VSG meeting 2, 171.*

When you are driving it's not very safe. I mean it's when you are coming up to a junction with two lanes and you have got to decide which lane you are going in

before you get there. So it's like being on a driving test isn't it, you've got to talk to them as being an instructor. That's what I found with Bob. *Monica. VSG meeting 2, 308-314.*

Errors in Sequencing and Omitting Elements of the Driving Task

Both groups discussed the act of driving and agreed that the task was one that is largely performed automatically without a high degree of conscious control. The relationship between driving and performing other daily tasks was also explored. Group members recounted instances of errors in carrying out everyday personal and domestic tasks and comparable errors observed in the driving task. Christine explained that errors in the ordering or omitting of elements of the task performance had been a feature of her mother's condition.

Christine. We were just saying though it's like a sequence though isn't it, driving, like getting dressed or riding a bike, like Jenny says. If there's a bit missing, like when they go and get dressed. Like my mum does, a couple of clothes on, because she's forgotten to put her jumper on... like that sequence.

Jenny. But I suppose when the sequence is working you just do it automatically don't you? *VSG meeting 1, 575-584.*

Difficulties with the sequencing of tasks were also identified as the one of the most obvious observable symptoms associated with the progression of dementia. Audrey explained that her husband had developed difficulties with the sequencing of a task and connected this with his reluctance to continue driving.

I don't know what the people think. I mean at the beginning my husband didn't look like there was anything wrong with him. You ask anybody. He just couldn't see those things at all and that was reflected in driving as well. We never had these sorts of problems. He'd just start to say, 'You do it.' He didn't want to do it. I never

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twigged at the beginning really. I mean, we were in that sort of no man's land and we didn't know what was going on and things were peculiar, and he just said he wanted me to drive. 'I'm tired.' He just couldn't do things in a sequence. Whatever it was. He looked okay and talked okay. And Tom was okay. It wasn't just one specific thing, but lots of tasks. He couldn't do a cooking task or put the things back in the cutlery draw, is another example. He did it beautifully, but in the wrong order, you know. *Audrey. VSG meeting 2, 246 – 260.*

Changes in Driving Performance

Both of the group's members discussed factors that would indicate problems associated with a decline in driving as a consequence of dementia. Groups discussed the difficulties of attributing driving behaviours and errors, especially those that were considered to be subtle, to an impairment of cognition and judgement. The experience of group members indicated that one of the main features of the consequence of dementia upon driving was a noticeable alteration to the person's usual driving pattern. These changes did not necessarily render the person's driving unsafe but provided a clear indication of an influence upon functioning.

A recurring theme during the meetings of both groups was the manner in which driving was affected by the degenerative process of dementia. Detecting the point at which driving becomes affected by the symptoms of dementia is a common problem for family members. Problems are often only identified and addressed after significant events. A number of examples of significant changes were provided during the group meetings and involved incidents of collisions or near collisions.

I had a new car and my husband went to the tip with some stuff. When he got back with dints in it! By god, what have you done? [He] backed into a skip that

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was waiting to put your stuff in. I thought that's not right. I mean he's always been a good driver you know. Because he's worked all over the country and he's always been really good. So then I started taking a bit more notice. He did it twice. He did that side then he did that side. And I don't know what he hit on that side. He said it wasn't him, but there was only him in car, and so then you start noticing these little things. *Jenny. VSG meeting 1, 175 -183.*

Then you start noticing these little things like really the crux of it was, we would go to Blackpool a lot, and the car could take itself, you know. And he gets to this roundabout and goes that way [incorrect direction]. Well you know... it floored me. And he said 'Oh what am I doing, what am I doing?' *Monica. VSG meeting 1, 182 -192.*

Detection of decrements in driving safety for family members and health professionals was felt to be more difficult when the problems associated with driving were relatively mild. Members of the VSG were able to recall examples of barely discernible changes that initially provoked concerns in the early stages of the disease.

I don't think it would have come up as anything. I think it was probably an indication but we didn't know. We only found out two years ago but I think it's probably... No she was just driving very slowly. *Marian. VSG meeting 1, 153 – 159.*

Members of the group agreed that rather than being able to identify a particular incident or occasion where the driver had acted in an unsafe manner, it was the unconscious response of the passenger that acted as an indication of a change in the person's driving. Group members described no longer being relaxed when travelling as a passenger and experiencing an increase in the alertness and vigilance as a response to the subtle changes in driving behaviour. Christine provided a good example of the gradual change in her vigilance when travelling as a passenger with her husband.

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So, I suppose as a passenger you know something, there is that [thing] making you think, hang on a second, I'm not... I don't... something's changed. I don't feel as comfortable now as I did before. And then I realised. I used to knit while he was driving. *Jenny. VSG meeting 3, 153 – 159.*

Group members also explained that minor errors made by the driver were often explained by the driver and blamed on other drivers or the passenger themselves.

I noticed he was getting too near them you know or going faster than he thought he was going and I'd be saying you are going to fast here. 'No I'm not, no I'm not.' And then like you say at roundabouts. And then when I said something it was my fault because I was talking to him. *Marian. VSG meeting 2, 183 – 186.*

Implications for the Information Pack: Discussion

Both groups considered that mistakes made by drivers to be typical of everyday driving and examples of mistakes made or witnessed were discussed at length. It was also the opinion of both groups that the scale of driving errors was not necessarily indicative of problems related to an impairment of cognition. The frequency and nature of the driving error however were considered to have relevance in identifying whether the cause of the error might be attributed to a decline in cognitive function.

The ability to recognise and respond to events on-road is an action that occurs largely without the necessary awareness of the driver. Predetermined patterns of movement are engaged in response to visual and auditory stimulus from outside of the vehicle (Charlton and Starkey, 2013; Harrison, 1999; Summala, 2000). That is not to say that driving is entirely an automatic process but much of the operation of the vehicle occurs outside

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consciousness, enabling the driver to dedicate more attention to threats and hazards.

Members of the VSG group likened this to other familiar tasks that demand very little conscious engagement such as dressing or feeding. The disruptions to learned automatic patterns of behaviour in response to events was considered to be a vital element of the identification of driving errors associated with a decline in cognitive capacity.

The experiences of the group members suggested that the errors committed by the people with dementia tended to be associated with a failure of the automatic and unconscious actions of the driver in response to given situations. This was well illustrated by Shirley and her descriptions of the errors experienced by her husband who, being a retired approved driving instructor, presumably retained a high degree of driving skills prior to being diagnosed with dementia. Common agreement was reached across both groups that driving errors indicative of dementia were not a decline in the skill levels of drivers or a failure of the person to recall the correct procedure at a given traffic situation, but rather changes in behavioural response on a more fundamental and automatic level.

The presence of visuospatial deficits in people diagnosed with a dementia and particular Alzheimer's disease have been reported to be present in people with mild AD (Hope et al, 2001; Quental et al, 2009) but was a feature that had only recently been recognised by members of the health professional SIG. This may have been because the greater proportion attending memory clinics had been diagnosed with an Alzheimer's type dementia, with the main focus and most prominent feature in the early stages of this condition being the decline of memory recall. Subtle decrements in visuospatial awareness may also be difficult to readily identify in less complex situations. The experiences of the

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relatives of people with dementia in the VSG however indicated a number of examples of impairment in the person's visuospatial awareness when driving.

The judgement of the position of a moving vehicle in relation to its surroundings is a sophisticated automatic process that occurs continually and needs to operate independently of conscious control throughout the process of driving (Ott and Daiello, 2010). As described in the literature review section, awareness of the position of the vehicle relies entirely upon spatial judgement, without the usual sensory feedback available to us, such as proprioceptive awareness, when judging the movement of our bodies within our environment. Relatively minor disturbance of the visual processing elements of the brain that connect occipital and prefrontal regions of the brain, particularly in the right hemisphere, impair this judgement and can result in significant changes in driving safety (Snyder, 2005). A common theme of the members of the VSG was the changes in proximity to stationary vehicles when overtaking. This action demands that judgement of distance to obstacles immediately to the side are made at speed while vision and selective attention is focused upon events to the front. Modest changes to this capacity can result in significant misjudgements. A further manifestation of a visuospatial disturbance in the task of driving may be the inability of the driver to hold a steady course on the road or to remain in the defined lane. Difficulties in following the subtle movements of the course of the carriageway were seen as erratic road positioning by group member.

The VSG reported a number of occurrences of driving extremely slowly in busier traffic situations or delaying moving off at junctions. Incidents of becoming overwhelmed in traffic may be the driver's response to difficulties in dividing attention between events in more complex driving environments. Two particular elements of the ability of a person to

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divide their attention effectively when driving were identified during the research process.

The first related to dividing attention between the operation of the controls and events outside of the vehicle. The second focused upon dividing attention between competing events in the traffic environment. Slower driving offers the driver additional time to evaluate the constantly changing situation and allows greater opportunity to appraise situations effectively. Reductions in cognitive efficiency may place excessive demands upon cognitive resources, resulting in a failure to initiate responses of lesser importance to the safe completion of the task, such as the operation of non-essential controls, or lead to a slowing of decision making. Decisions when driving usually need to be made quickly and involve a simple choice of whether it is safe to proceed or not in the traffic environment. These decisions are also informed by countless previous similar experiences, of which the vast majority have all been successfully achieved. Driving decisions do not involve long periods of conscious contemplation but are made quickly and much of the information processing takes place without the need for conscious engagement. Dijksterhuis and Nordgren (2006) provided explanation for advanced cognitive performance in decision making when conscious analytical strategies are not employed. They propose that intuitive decision making emerges from a large capacity cognitive process that is capable of evaluating a great deal of sensory and experiential information and integrating them into swift decisions automatically. This system is better able to manage complex and information-heavy situations quickly than conscious decision making processes. The VSG proposed that consistent errors of judgement in these situations were considered to be indicative of an impairment of the process of decision making.

The task of driving is heavily dependent upon the completion of complex sequencing of actions, not only for the operation of the vehicle but also for the safe interaction with the

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environment. Attributing errors to omission or to poor sequencing with certainty is difficult and driving errors may have their origins in a number of sources making definitive identification difficult. Similarly, although driving requires the timely interaction of specific actions subtle omission or sequencing errors may go unnoticed until the consequence of the error is conspicuous in its threat to safety. For example, failing to release the parking brake or omitting to fit the occupant restraint when moving off may not directly impact upon the drivers safety but failing to ensure the road is clear of approaching vehicles to the rear is likely to result in collision. A number of driving errors of people with a diagnosis of dementia emergent from the group discussions related largely to sequencing and omission errors. These errors were considered by the research groups to be indicative of dementia because they were absent in the driver performance prior to the development of the disease. This appears to support research carried out in an analysis of the preservation of action based memory in people with a diagnosis of AD (Rusted and Sheppard, 2002). This study followed a small group of people over a four year period and monitored their ability to complete the task of making a cup of tea. The study concluded that the primary errors observed were those of omission and sequencing although omission errors were more common than those of sequencing. The inclusion of the sequencing and omission errors in the information and screening tool was considered to be valuable. These errors were familiar to the group members and considered to be of significance in the safety of the drivers involved.

Both groups agreed that changes in the driver's behaviour or performance were an important indicator in assessing when dementia began to affect safe driving. Although subtle changes in driving behaviour over a period of time may not be immediately recognised, the level of alertness and vigilance of the passenger tended to increase. This research revealed that although passengers did not feel unsafe when travelling with the

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driver they had experienced a sudden awareness of a heightened vigilance when travelling. Passengers became actively involved with managing drivers as opposed to previously being a passive traveller. This was well illustrated by a member of the VSG explaining that she had previously used the time travelling as a passenger to knit and then realised that she no longer knitted in the vehicle and monitored her husband's driving instead. The transition from knitting traveller to active monitor had not been abrupt and she could not recall a specific incident that had precipitated this change. This process may then progress to an increase co-piloting and providing verbal prompts to assist the driver in managing situations of increased complexity.

Changes in the driver's propensity to collide with other vehicles or stationary objects were acknowledged as a more obvious indication of changes in driving. Although this might appear to the independent observer a clear indication of the deterioration of a person's driving, collisions of this type were reported to be slow speed scrapes or minor misjudgements when reversing and were frequently dismissed as non-fault incidents. Uncertainties regarding the person's deteriorating capacity to manage driving were only aroused after repeated similar incidents.

5.6 Planning for the Future:

Both groups agreed that a lack of preparedness for the loss of driving entitlement contributed significantly to difficulties associated with cessation. Groups explained that both health professionals and people with dementia lacked awareness of the requirements and alternatives following diagnosis and in many cases the issue of driving was not discussed until the point of being asked to cease driving. A recurrent theme from both groups suggested that an early awareness and an active involvement in the process of

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driving cessation was a factor in aiding the transition. The VSG members explained that a lack of self-determination in the process made ceasing driving more difficult. The value of information at the earliest opportunity was considered necessary in enabling the person with dementia to play a more collaborative role in their relationship with medical practitioners involved in their care. Janice suggested that patients should be encouraged to seek an active collaboration with their general practitioner or consultant.

So there might be a reason why they would want you to stop driving in the doctor's eyes, but I think what we need to do is to pinpoint and say driving might be an issue and that maybe you need to discuss it with your GP and you definitely need to inform the DVLA - that's one of the major things. *Janice. VSG meeting 4, 146 - 152.*

Similarly, Cath highlighted the difficulties of medical professionals in making judgements regarding a person's continued driving safety without a satisfactory dialogue with the person or the ability to gather sufficient and reliable evidence.

I think the screening tool would empower GPs as well because I think sometimes the GPs really don't know and then the consultant psychiatrist only comes and talks to us whereas the GP would have something were they feel a little bit more empowered. *Cath. SIG meeting 2, 187 - 190.*

Living after Driving

The effects of driving cessation were discussed in detail by both groups. The experience and perspectives of the groups however differed somewhat. The SIG members were acutely aware of the consequences of ceasing driving. Experience centred upon the change in the overall level of participation in instrumental activities of daily living of the person and the detrimental effect this had upon established life routines and broader well-being.

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But a lot of the partners don't drive. You think, if Harry doesn't drive, I'm not going to be able to get to the shops, I'm not going to be able to get to the ... It's affecting their life isn't it? *Rebecca. SIG meeting 1, 219 – 222.*

The VSG discussed the issue of driving cessation at length. The group members explained their experiences and expressed the ways in which the move from using a privately owned vehicle to public transport affected their daily routines. Neville richly illustrated the practical difficulties of using public transport.

When you have to give up driving, a lot of people, particularly older people, use their cars to go shopping. So then you are going to have to think of getting a taxi to get your shopping or get a bus. Then you've got all the shopping that you are carrying and you are getting on a bus. People get mixed up. They get on the wrong buses. That's fraught with more problems and difficulties [rather] than just bunging everything in the back of your car and going two hundred yards up to your house. You set off and they have notices up you haven't to stand up until it stops, but they don't stop if you don't stand up... My wife sometimes... They have set off before she has sat down but you can't hold onto your shopping and hold onto the rail to get on and off. *Neville. VSG meeting 2, 588 - 598.*

Janice explained that using public transport also demands a greater level of interaction with others using the transport which can be concerning and present unfamiliar problems for people with dementia.

I had the misfortune of having to get a bus from my house here and it's only a straight road. I was terrified. Apart from the fact that people feel that they had the need to talk to you. I don't want to talk to anybody first thing in a morning. I couldn't stand up, you are going backwards and forwards as they are stopping. It took years off my life. *Janice. VSG meeting 2, 600 - 607.*

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Proposals to assist with replacing driving were felt to have met with limited success.

However, a number of suggestions relating to alternatives to driving were already employed by many of the group members who acted as carers of the family member with a dementia. Alice, a member of the VSG had employed many of the strategies discussed in the group sessions.

The things we suggested I already do. I have my prescriptions delivered, I order them. I get my meals delivered too. I can get the hairdresser to visit but if the weather isn't bad I just get a taxi. *Alice. VSG Meeting 5, 185 - 188.*

Implications for the Information Pack: Discussion

Members of the SIG described experiences of patients who had considered driving soon after diagnosis and actively prepared for eventual cessation. These patients were reported to have managed driving and the move to end driving with greater ease and success when compared with those patients who had not. In contrast, patients who had not paid regard to driving earlier were more likely to find the loss of driving more challenging. Although recognition of the benefit of early planning of driving with dementia was recognised, a number of the SIG reported that driving was often a difficult issue for them to address. Reasons for this were that driving was often not a pressing issue on an initial contact but also health professionals were uncertain of licensing process, the scope of their role and necessary inputs.

The transition from driver to non-driver presents a number of challenges. The SIG's broad impression regarding the attitude of family members towards driving was that they were typically defensive of the person's ability to continued driving. SIG members reported family members minimising or denying difficulties with driving and delaying attempts to

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address the issue. VSG members offered a different perspective of the role of family members. VSG members explained that although family members may have concerns regarding the person's driving safety, involvement in the process of revoking driving entitlement would harm the relationship between the driver and family member (Bernhart and Penazola, 2013). The group members also expressed a deep sense of guilt associated with responsibility for the person being forcibly stopped from driving.

The SIG members discussed the importance of driving as a key component in managing household activities such as shopping and attending appointments. Alternatives to driving were discussed and suggestion broadly grouped into two approaches. The first approach was to consider physical alternative modes of transport such as private hire taxis, buses, trains and lifts from friends and family. The second approach examined the value of reducing the need to travel by arranging for the goods or services to be delivered to the person's home. The VSG members, although understanding of the need to identify a replacement for driving, were broadly doubtful whether public transport could offer a comparable alternative. Concerns centred on the ability to manage the complexities and the physical demands of travelling by public transport. Members of the SIG stated that the cost of taxi services, even for relatively routine journeys might be prohibitive. The VSG and SIG recommended that examples should be included in the information section of the final document with the aim of encouraging early contingency planning and testing of possible alternatives for their suitability and to promote familiarity.

5.7 Chapter Summary:

Chapter five has described the collaborative development of the data that formed the basis of the information section of the final document. Both research groups considered the lack

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of consistent and reliable information regarding driving with dementia to be a fundamental issue and one that ought to be addressed by the research. Both groups considered societal understanding of dementia and explored how structural stereotyping negatively affected attitudes towards people with dementia continuing to drive. The meanings associated with the action and role of driving were also examined. The chapter considers changes in driving performance as a consequence of dementia and determines how these may manifest in behavioural differences from typical driver behaviours. Finally, both groups explored driving management and cessation strategies. Both groups agreed that early involvement in the monitoring, planning and decision making process would enable people with dementia and their families to be an integral part of the management of driving. Both the SIG and VSG groups were also clear that people with dementia should be made fully aware at the earliest opportunity of the eventual need to cease driving, as a consequence of the diagnosis of dementia. This was considered key in enabling the person opportunity to reflect and actively participate in practical planning for eventual cessation. The next part of the thesis presents the findings relating to the creation of the screening element of the final tool.

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Chapter Introduction:

Chapter six will present the findings in relation to the screening element of the final tool. As with the previous chapter, the data are organised and presented to reflect the themes emergent from the group meetings. These were then used to explore, inform, develop and finally construct the screening elements of the final pack. A discussion of the findings is included within the chapter, immediately following the presentation of the findings, to enable the reader to remain close to the development process and detail the relevance to the components of the screening tool. The chapter will again replicate the structure of the final tool including the findings relating to the screening element of the final tool.

6.1 Decision Making and Driving Risk:

Decisions about a person's driving safety were explored by both groups. From group discussions it emerged that the process of evaluating a person's driving safety commonly comprised three points in the decision making process: the individual with dementia, family members and the health professionals involved in their care. The influence and level of the contribution of each of the parties involved varied markedly according to a number of factors. Factors relating to the input of the individual and family members have previously been addressed in chapter five.

Health Professional Role in Continued Driving

The role of the health professions in driving for the person with dementia varied between health professions within the group and did not appear to be clearly defined. Alan, a SIG member considered the CPN's role to be one of advising that the client inform the DVLA of their condition only.

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So, as a CPN, why would I want to start doing a screening tool with people when I've done my bit by saying that you need to tell the DVLA. I don't need to get involved in that side except do the legal side. Why would I need a screening tool?
Alan. SIG meeting 1, 115 – 119.

This view was not shared by all the group members however. Other members of the group felt that they had a more active responsibility to monitor the safety of the people under their care. Donna expressed concerns regarding her clinical responsibility and the scope of her professional role.

Any professional, what so ever, that goes into someone that is driving, [has a responsibility]. Because, sometimes we have a complex situation where no one is taking any responsibility. *Donna. SIG Meeting 2, 52 -55.*

The process of evaluating a person's driving safety as part of the DVLA medical investigation of fitness to drive was considered to be, in some cases, ad-hoc. Members of the SIG described health professionals' difficulties owing to a lack of relevant information and structured guidance.

It's a difficult one. I mean I think we have to do something because the current DVLA form is just terrible. It's just tick boxes that just tell you nothing, isn't it? Quite often the consultants are saying to me 'Well you see them, you fill it in and I'll sign it'. *Joyce. SIG meeting 1, 406 – 408.*

The members of the SIG discussed a lack of clear responsibility and planning by the care team in relation to driving. Rebecca provided examples where team members were unclear who should take the responsibility for decisions about continued driving and how decisions should be made.

I can see there's a real role for it. Because, obviously we give the information to the service user that they must let the DVLA know, by law, but I think it might be a

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really good tool for GP's because the GP then is the point of [contact]. Once the service users inform the DVLA a lot of our GP's are then, 'I'm not in a position to be able to make that decision.' They then ask our consultants. I don't know whether that happens in your area? And the consultants go out and what the consultants then do is go and speak to the service user and the family and say 'how are things?' or speak to us and there's no specific defined tool that they could use. I could see that how for the consultants and the GP's it would be quite a good tool to use. *Rebecca. SIG meeting 1, 173 -180.*

The VSG members also discussed their experience of the health professional's role and offered an alternative perspective upon their position. Marian explained that health professionals were well placed to play an important role in supporting family members with difficult decisions regarding driving owing to their expertise and influence.

I don't know who told him to not drive, I've got a feeling it was probably my mum. But my mum pays for it, you know. It's my mum that gets it in the neck that he doesn't drive anymore. Whereas if somebody, anybody in a uniform had said, 'sorry but really you can't drive' he'd have taken it like that. But because my mum said I'm not getting in the car with you again, it's, like you say it's agro. *Marian. VSG meeting 1, 311 – 318.*

The responsibility and required actions of the health professional in relation to driving was an area of uncertainty for members of the SIG. Health professionals were unclear about the necessary and correct course of action required if concerns about driving safety were exposed during assessment or treatment interventions. Clear differences in practices, opinions and action were apparent during the meetings.

Donna. What is our duty of care? We don't want to be phoning the DVLA up for everyone, so I inform the GP and inform the consultant, but I might be wrong. You send a copy of your letter, but it is our duty of care because we are like the ones. *Rebecca.* I wonder if we should be sending a copy maybe to the DVLA. I never send anything to the DVLA.

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Donna. I mean, I've got a duty of care. If you've gone to somebody like you say and you've said 'I don't think you should be driving' and you have sent a copy of a letter to the GP and the consultant then one should go to the DVLA. *SIG meeting 2, 283 – 295.*

Current Methods of Monitoring Driving Safety

The members of the SIG explained that driving is not routinely addressed in the initial interactions with patients. Donna described her usual assessment process during the initial contacts with patients.

I don't even get round to doing the ACE - R on the first visit. It depends what stage you are at on the first visit. Definitely on the second or third visit. Because at the moment, if someone is scoring reasonably well on the MMSE, and they haven't got any spatial problems and the family say there's no accidents and they feel quite safe in the car then it doesn't go any further. *Donna. SIG Meeting 2, 91 – 97.*

Members of the SIG explained that judgements about a person's driving safety relied upon a subjective assessment of the individual. Clinicians reported having very few sources of reliable evidence and therefore information was gathered from a number of sources. Cath explained that this included examination of any evidence of collision on the person's vehicle.

When we walk in, you clock [notice] whether... and I know it sounds really awful... but are there scratches on the car? You know, how often do we look at the car? I know we shouldn't be doing that of course but that's what we've got at the moment, our judgement. *Cath. SIG Meeting 1, 245 – 248.*

The SIG members explained that clinical judgements were used to evaluate whether driving was likely to be affected on the basis of conversations during visits.

We're just making a judgement really. As clinicians you do really. It's part of it. It's gathering [information]. All that comes in doesn't it and gets synthesised in

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your head as an experienced clinician and then suddenly you think, you don't know why, but suddenly, I've got a feeling. *Rebecca. SIG meeting 2, 123 – 129.*

Formal Screening

Current practices of all group members included formal screening tools of general cognition in their usual practice. Cath, in discussions with the SIG indicated that on the initial contact with a new patient, a general screening tool would be used to provide a general overview of cognitive function.

So in an admission, when we do a full mental health assessment obviously [it] incorporates the Addenbrooks. You're looking at your visuospatial and your perceptual difficulties on your Addenbrooks aren't you? And if they are throwing up concerns then would you be thinking in addition, like we do with GDS on somebody with depression, and doing an extra [evaluation]. *Cath. SIG Meeting 1, 139 – 144.*

Members of the SIG explained that if difficulties with visuospatial functioning were identified, then questions about a person's driving safety would be raised.

Assessment tools are not available to health professionals however, if concerns about driving are raised from this initial screening.

I don't think that they get screened, the driver. We don't screen the driver because there isn't any screening whatsoever for driving. I actually asked a neuropsychologist if there was any test for driving and she said no, one doesn't exist. You can only look at things like attention, concentration, spatial awareness. *Cath. SIG Meeting 2, 228 – 232.*

The SIG members relied heavily upon specific testing that evaluated executive functioning, visuospatial functioning judgement and memory. Donna described the screening tools she routinely employed in assessment.

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I mean we put a lot of emphasis on the visuospatial tasks like the clock drawing and the pentagons and in actual fact we don't put a lot of emphasis on thinking well has that person been able to construct a sentence. It's something to look at to see if there is any correlation. *Donna. SIG Meeting 2, 385-388.*

The value of cognitive screening for health professionals was considered to be an important element for health professionals in their approach to obtaining useful information. Its inclusion also provided the opportunity to obtain information relating to specific areas of cognitive functioning in particular visuospatial awareness and executive functioning.

The VSG also discussed the use of screening and the value of self-screening or screening carried out by family members.

Who's going to do this [screening tool]? Is it going to be the person with the possible dementia or is it going to be their carer? Who's going to look at it? I'm wondering if it would be worth... if a carer or other the person, who goes out with the person, goes up to the assessment, could they both do one? *Alan. VSG meeting 3, 214 - 218.*

Implications for the Screening Tool: Discussion

The role of the health professional in addressing driving is an important topic in terms of the effective monitoring and support of driving for the person with dementia. It also has implications for the design and value of the screening tool. Differences of opinion in the SIG were expressed regarding whether driving should be considered alongside other aspects of the patient's care addressed during an intervention or whether simply informing the patient of their responsibility to notify the licensing agency satisfied the obligation of

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the health professional's involvement. SIG members described a range of approaches from those who did not address driving unless a significant issue was determined to those who would routinely contact the DVLA. All members of the group expressed a degree of uncertainty however regarding their responsibilities as a health professional.

The health professional role in dementia care, particularly in the early stages of the condition is one of support and monitoring of treatment and acting as the primary interface between patient and medical services. A close, personal working relationship with the person and their close family is necessary to ensure that any interventions are responsive to need. The topic of driving and the duty of care are perhaps problematic for the health care professional because it may be the first or only principal topic of divergence from this role. This conflict is particularly acute when the health care professional feels at liberty to report their concerns to either the doctor or the licensing authority against the wishes of the patient. The potential disparity between the health professional and the patient regarding the person's driving safety can be difficult to resolve because of the complexity of evaluating driving risk for both parties. For the health professional, addressing a subject which places them in the role of licensing arbiter as opposed to care provider can be unsettling. This is further compounded by a perceived lack of reliability of evidence available and clear guidance as to the correct course of action for the health professional. The SIG agreed that greater awareness of the issues of driving on the part of the health professionals would enable them to adopt a supportive rather than a punitive approach to driving.

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Questions regarding driving safety were occasionally prompted from information obtained about the person's cognitive status from a variety of short cognitive screening tools, together with reports from the patient and their carers. Members of the SIG explained that they would also gather information from a variety of sources such as reports from family and from the condition of the person's vehicle. Evidence of scratches or bumps to the vehicle were considered to be useful in determining whether the person's driving was becoming problematic. SIG members also agreed that information regarding a person's broad function would raise concerns about the person's driving safety for the experienced health professional. Members of the SIG accepted that the current methods of arriving at a decision regarding a person's driving safety were inconsistent and relied heavily upon the health professional's level of expertise. The overall judgement of the experienced health professional was however considered to be useful in evaluating the patient's condition and possible decrements in driving safety. Members of the SIG were of the view that the prototype screening tool should include elements that influence the judgement of the expert practitioner. Members of the VSG considered the potential value of the screening tool to family members. The value of self-reporting and a section of the screening tool completed by the person with dementia themselves were considered valuable in the monitoring and collaborative management of driving.

Members of the SIG described their comfort and confidence in utilising screening tools to assist their interventions for people with dementia. A number of screening tools were employed to inform the health professional's practice and to provide information regarding deficits in the particular cognitive domains. Members of the SIG expressed differing levels of confidence in the cognitive tools results but considered them to be useful in providing evidence and establishing a baseline for their interventions. The SIG discussed the value of

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a tool being administered across the team of health professionals; in particular the GP who it was felt often had very little contact and was asked to make a judgement upon driving safety. Members of the SIG reported that the driving safety of an individual with dementia was occasionally neglected because of a lack of clear responsibility to support and monitor driving, resulting in the issue being overlooked.

Data gathered from the SIG meetings revealed that although driving could often be a fringe issue at the commencement of interventions, it frequently later emerged as a critical concern that required immediate and difficult action. SIG discussions illustrated the manner in which health professionals lacked confidence in their understanding of how driving safety might be affected and often they felt that other professionals were better placed to make decisions. The members of the SIG felt that the use of a screening tool and more specifically the inclusion of an information section would be of great assistance in the understanding of driving and dementia not only for the person and their family but also to furnish their own understanding.

6.2 Monitoring and Recording of Driving Performance:

The group members of the VSG explained that the decline in driving safety had been a process that occurred over an extended period of time. Members described changes to the person's functioning had in many cases taken place unnoticed by close family members. Doubts in relation to the person's wellbeing were often only prompted by a single, significant incident or by the reports of outside observers. On reflecting upon the changes in the person's behaviour however, group members felt that evidence of deterioration in the person's condition had been apparent for some time prior to this final realisation. The VSG examined the value of documenting events and Marian suggested that much of the

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evidence of deterioration that is not immediately visible to close family members may be more apparent if a conscious effort is made to record them.

I was the last person to know, I don't know about everybody else, that my husband had got dementia. He's fifteen years older than me and I just thought that he was turning into a cranky old man... I did! Because my dad died when he was seventy, so I didn't have the experience of my dad and I just thought, oh that's what old men become, cranky and nasty at you. I was the last to know, and I just kept mentioning it to my daughter, I said Brian keeps doing this, and that and the other she just said, 'Mum, do you not think you should take him to the doctors?' I said, 'Why, what is it?' *Marian. VSG Meeting 5, 412 - 420.*

I think it's a good idea [recording of incidents]. Don't you think that when you write things down you remember things better? So you can still remember them after you've written them down. *Alice. VSG meeting 5, 441 – 443.*

It was agreed with the group members that a written record of re-occurring events would be useful. Members cautioned however the potential for the recording of errors to generate conflict between the person with dementia and family members.

Family Reporting

The role of family members in managing and monitoring driving safety for people with a dementia was explored by both groups. Cath, a SIG member explained that they have limited sources of information and frequently rely upon family reports in their decision making about the person with dementia when conducting assessments in the community setting.

At the moment I'm making a subjective [decision]. I'm just going by what they are telling me, what behaviours I'm noticing, what a relative tells me and just the visuospatial [testing]. *Cath. SIG meeting 2, 78 – 84.*

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The members of the SIG considered the reports of the family an important resource and suggested that this element may offer useful information relating to the person's driving. The group contrasted the findings of current screening tools with reports received from family members regarding a person's driving performance.

What are your thoughts about including family? Because quite often they'll do very well cognitively. We don't pick up any concerns but the wife or daughter will say, 'I'm a bit worried about their driving,' because they've been out with them and they notice something. So I think it would be important that they had some input they could make. *Joyce. SIG meeting 1, 188 – 194.*

The members of the VSG also placed a high value upon the input of family members. Group members recommended that the screening tool consider and include responses from the person with the dementia but also, in addition, incorporate the observations of close family members. Shirley cautioned however that family members may fail to recognise the severity of the errors owing to the changes occurring incrementally over a period of time.

Because if somebody went through it with the person that they go out with on a regular basis, they would know them. Because the person who's doing the driving might not think that they drive too close so it might be worth thinking about it being done by both people. *Shirley. VSG meeting 3, 372 – 375.*

The issue of the reliability of family reporting was questioned in both groups. SIG discussions questioned the validity of observations of relatives who were non-drivers or those who had very little driving experience. Alan expressed his uncertainty whether the perspectives of non-driving passengers were entirely reliable.

A chap spoke to me the other week about driving. There weren't any concerns as such, but I think his partner mentioned something, but he said, 'I've driven for Forty

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years' as most people say, not to be disrespectful, but he said 'to be honest she's never driven and she doesn't see things as a driver.' I thought, well there is something in that. Somebody who's never driven, they might just be a passenger. Like, we all go on a plane on holiday and we have an idea what a pilot does, but we don't know. We couldn't fly a plane could we? So there are certain things that are probably not valid that she's saying. *Alan. SIG meeting 1, 224 – 233.*

The reliability of family reporting was questioned because of the difficulties of family members to recognise or acknowledge changes over a period of time in the person's functional status. The task of recognising changes in the person's driving and concluding that these changes are likely to render a person unsafe driving was felt to be extremely problematic for family members. Both groups stated that occasionally family members tended to ignore or minimise problems associated with driving.

We just tend to say, 'how do you feel?' and they say 'Ooh he's safe, ooh he's confident, and, you know, he might sort of lose his way occasionally... but I'm always with him!' And they're telling each other they're all right! *Donna. SIG meeting 1, 201 – 205.*

The VSG established that a lack of understanding regarding the consequences of dementia in relation to driving resulted in some family members having difficulties with recognising the significance of driving behaviours. Group members added that difficulties with an acceptance of the diagnosis may lead family members to attribute problems observed with driving to poor driving standard and typical driving errors.

But it was really difficult because I spoke to his sons and one said, 'Well, he's only like every other man of his age.' And I thought, no, sorry, and the other one said, 'Well, I don't think you should tell the doctor.' So to try and keep the peace you know with the step sons. *Monica. VSG meeting 1, 427-431.*

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The impact of driving cessation upon family and spouses was considered a possible factor in influencing how difficulties with driving were responded to. Christine pointed out that some family members would be unwilling to acknowledge problems because of the harmful effects of the person ceasing driving upon the family routines.

You might have a carer who does want them to drive. It might be that is the situation. Because they can't drive, so they want that person to drive to get them from A to B. It might be that they just ignore the fact that they are getting confused or having bumps. *Christine. VSG meeting 3, 426 - 431.*

Although a number of weaknesses were identified with family reporting, the inclusion of information from family members was considered likely to be useful in identifying particular events or behaviours that may be indicative of deterioration in driving safety. The research groups explained that increased awareness and knowledge of the possible impact of dementia upon driving safety would assist with the monitoring process.

I think some of the relatives have got a vested interest. But the other side of it is they don't perhaps look at the pointers that may be on the screening tool, like how close does your husband or your wife drive to the corners. Depending on what you put on the screening tool. It's when it opens up an awareness of clues for the relatives. *Rebecca. SIG meeting 2, 105 – 111.*

The significance of family reporting was consistently emphasised during the meetings. Janice pointed out the value of close family members in detecting subtle changes in the person's well being and behaviour.

It's usually... it's the carers who have said 'well they've got a diagnosis [of dementia] now but I've noticed that there's been a change over the last two or three years. *Janice. VSG meeting 3, 413 – 415.*

Self Reporting

The self evaluation of driving performance by the person with dementia was used by a number of the SIG in monitoring a person's driving safety. Lisa explained that people considered to be at an early stage of the disease with a mild impairment of cognition were questioned regarding driving and the information included in the decision making process.

I've had, a bit of a flip side. I've had a couple in recent weeks where they've actually, you know, they're showing signs. Eventually he will get a diagnosis of a dementia. But they're actually saying 'if I knew I wasn't going to be safe I will stop driving' and that sort of insight. But yet, you know that at this moment they're probably safe enough. But it's that reasoning that they know things. *Lisa. SIG meeting 1, 321 -326.*

Cath. I suppose [screening for] driving would be good practice to do it with everybody who's driving.

Alan. Why would you do that?

Cath. Because at the moment I'm making a subjective [decisions]. I'm just going by what they are telling me. *SIG meeting 2, 78 – 80.*

The weaknesses of relying upon an individual's self assessment of performance were discussed. Members of the group identified a significant limitation of the reliability of self reporting information owing to the issue of insight.

It would be quite interesting to see whether there is any correlation, for people that have only got a partial insight into their cognitive impairment as opposed to people who've got full insight into their cognitive impairment. If there's any sort of correlation with people who think that they're still safe to drive when they've only got a partial insight into their cognitive impairment. *Donna. SIG Meeting 1, 352 - 357*

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The VSG suggested that a person's lack of insight into their difficulties had a significant influence upon their ability to make a judgement regarding their own driving safety.

Members of the VSG that attended as carers of a person with dementia insisted that driving was not discussed with the person with dementia as this frequently lead to the person wishing to return to driving. Shirley explained that although her husband had significant cognitive impairments, he firmly believed himself to be able to drive safely.

Donald is definitely not aware... He thinks he is very safe... He is a lot of the time but I don't let him drive because sometimes he is not safe. *Shirley. VSG meeting 4, 298- 299.*

The members of the SIG explained that although self reporting has limitations relating to the reliability of the information gathered it continues to have some of value in monitoring a person's condition.

The man I've been concerned about he said 'well I don't drive at night' and he's quite insightful and he recognises he has got some problems. 'On a bad day I just don't get in the car, I just get in when I'm feeling good.' *Donna. SIG Meeting 3, 121 -126.*

Physical Elements of Driving

The effect of physical impairment upon the ability to maintain safe control of a vehicle is perhaps poorly considered when screening drivers with dementia. Problems operating the vehicle controls may however result from a reduction in praxis skills or may occur because of other physical conditions unrelated to the diagnosis of dementia. Difficulties associated with the operation of the vehicle controls were discussed by members of the VSG.

If you've got weakness in your limbs you don't have the force to apply pressure. We've had a weakening of limbs over a long period of time. That was one of the

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problems Tom had. He was feeling for the brake, struggling finding the biting point and keeping the accelerator steady, of course because of... weakening of his limbs. *Audrey. VSG Meeting 5, 407 - 411.*

In your neck and back as well, and your shoulders. Turning around to see other traffic is really hard. *Alice. VSG meeting 3, 51.*

The influence of fatigue was discussed by a member of the SIG. The effects of poor tolerance to exercise were stressed as a potential danger in maintaining driving safety. Cath explained that fatigue caused by poor sleep patterns or by physical exertion should be considered within the physical element of the screening tool.

You see my Dad's eighty this year and he's very fit and very well but he did have an accident in the car. He fell asleep [while driving] we think. *Cath. SIG meeting 1, 295 -296.*

Members of the VSG explained that fatigue is a common problem and most of the group members agreed that this fatigue shared many common features. Members described the person with dementia experiencing agitation, restlessness and tiredness. Jenny identified a feature common to the experience of most other group members.

My husband is worse when he's tired, and he's argumentative. It's worst in the late afternoon as well. They call it 'sundowning.' *Jenny. VSG Meeting 5, 286 - 288.*

Visual Elements of Driving

Similar to the physical components of driving, both groups considered vision to be an important element of driving safety. The difficulties with driving were associated with poor lighting conditions and with glare when driving at night time. This issue was considered to be a common experience for group members of both groups.

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You know if you driving, if you're driving home at night it's mostly taxi drivers I find that are all zipping around really fast and it is the glare. *Cath. SIG meeting 1, 314 -315.*

Is it just me or has anyone else noticed that lots of street lights aren't working these days. You find that where I live it seems the council have turned out the street lights to save money in the budget and it's really dark. It's making it difficult to see. Well for me, who I hope hasn't got a problem, it's making life difficult. *Brenda. VSG meeting 2 120 -126.*

Can I just add to that, a lot of people that I've had dealings with in the past find that at night it's okay, when it's black and white and during the day it's fine but it's in that in-between. When it's neither one nor the other. *Neville. VSG meeting 3. 35 – 39.*

Relationship between Driving and Performance in Daily Living Tasks

The relationship between safe driving and performance in activities of daily living was explored by both groups. VSG members suggested that one important element common to both driving and ADL tasks is that they are, for the most part, completed automatically. Prominent factors associated with failure to complete the tasks successfully were reported to be the inability to correctly sequence the task and omissions of particular stages of the task. This was discussed in relation to driving by Christine.

He didn't accept that. It just comes naturally, like getting dressed. He didn't see that he was getting it wrong [failing to stop] on the zebras or the pelicans. Because we never think about 'Ooh I've got to stop at this Zebra' do we? We just do it automatically. *Christine. VSG meeting 1, 586-589.*

The group also discussed the relationship with errors in ADL tasks and driving. Problems with IADL tasks were considered to be likely to also indicate problems with safe driving

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by group members. A number of group members indicated that failure to successfully complete familiar, everyday tasks related to difficulties experienced in the driving task.

My husband was looking for the sugar in the fridge. I wasn't there my daughter was, I'd gone to the hairdressers. But when I came back she said 'Dad's just been looking for the sugar in the fridge.' He didn't believe it wasn't in the fridge. It's the little things like that you know, if they drive a car you know they can't find the controls. *Jenny. VSG Meeting 3, 487 – 491.*

Members of the VSG recalled a number of their experiences with the person's failure to complete familiar task tasks. Shirley explained that these difficulties were not a consistent feature of the person's functioning but occurred only occasionally.

My husband is very practical but some moments he wouldn't be able to put a screw in properly, he'd be screwing it the wrong way. And then the next week he'd probably do it perfectly. Like last week he put a mirror on the wall no problem. And yet we tried to put a light together and I ended up doing it in the middle of the night when he was asleep. *Shirley. VSG Meeting 3, 410 - 413.*

The sequencing of tasks and omitting elements of the task were considered significant in the progress of the condition. Difficulties successfully completing activity of daily living tasks were felt to be indicators of a worsening of the condition and an element that impacted markedly upon driving safety.

I mean, at the beginning my husband didn't look like there was anything wrong with him, he could pass anybody. He just couldn't sequence things at all. And that was reflected in driving as well. We never had these sorts of problems. He just couldn't do things in a sequence. Whatever it was, he looked okay and talked okay. He couldn't do a cooking task or put the things back in the cutlery draw, is another example. *Audrey. VSG meeting 2, 247-256.*

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Members of the SIG were uncertain that the relationship between functional task performance and driving existed but felt that this was more dependent however upon the particular type of dementia.

There again I do feel that people may not be able to cook but would... they can drive. It's procedural memory isn't it. *Rebecca. SIG meeting 3, 428 - 429.*

Implications for the Screening Tool: Discussion

Both of the groups explored the sources and the reliability of information available to inform judgements of fitness to drive. There was broad agreement across both groups of the value of family reporting. The informal monitoring of a person's condition and performance in function appears to occur naturally and judgements from these sources already utilised to differing degrees by both family members and by the health professionals. Both of the group's members described that, for the most part, the family members were best placed to monitor and evaluate changes to the person resulting from the progress of the condition. All of the members of the SIG relied upon family reporting to monitor the progress of dementia and more specifically in relation to driving safety. A number of members of the SIG placed greater value upon information obtained from some family members than evidence obtained through formalised cognitive testing. This view appears to be supported by research investigating the reliability of family reporting in other areas of health care (Ellingson and Slutske, 2010). Both the VSG and the SIG concluded that the benefits of family reporting justified the inclusion of a formalised section for family reporting in the final screening tool.

Both groups cautioned that family reporting was not without its weaknesses. Concerns were expressed by both groups regarding the reliability of the information obtained.

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Reservations were expressed by the VSG relating to the difficulties of family members to recognise and accept changes. Family members were also felt to be influenced by stereotyping and a lack of clear understanding about the effects of driving and dementia. Both groups described the loss of driving as having limiting effects upon other family members who may be non-drivers. Weaknesses in the reliability of the information obtained from family members however may be reduced when used in combination with other information sources.

The groups discussed ways in which observations by family members might be formalised and recorded to increase its value as a resource in monitoring function and in particular driving. A number of the members of the VSG explained that they currently employed a strategy of keeping a record of important events and appointments and explored the feasibility of using written notes to record notable events when driving. It was suggested that a written record of events would provide a detailed picture of changes over time and clear evidence for the individual with dementia and those involved in their care. Members of the VSG who were carers for people with dementia expressed concerns however that completing written records of driving performance may lead to conflict between people with dementia and their families.

The inclusion of self-evaluation of driving performance was widely used by members of the SIG when monitoring the person's driving safety. In the experience of the health professionals involved in the study, the subjective experience of the individual was considered to be a key element in understanding the person's functional status at that time. Members of the SIG accepted however that the reliability of information obtained in this manner may be limited by deficits relating to memory, awareness and judgement, as these

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domains of cognitive function can be impaired by dementia. Similarly, concerns were expressed regarding the trustworthiness of self-reported information owing to the possibility of a reduction of insight into functional status. While reservations existed, self reporting was considered an extremely valuable information resource and one already heavily relied upon by health care professionals in the research. Evidence supporting its value suggests that people with a mild or moderate dementia are able to accurately expressed concerns and preferences and provide accurate evaluations of their own health status (Trigg et al, 2007). The importance of a self reporting element in the screening tool extends well beyond information gathering. Involvement of the person in monitoring of driving from the initial diagnosis was considered an essential element in the satisfactory management and eventual transition to driving cessation.

Because dementia is a condition associated with older age, other medical conditions such as musculoskeletal and neurological disorders may also be present. Both research groups recounted experiences of driving that were not directly associated with a cognitive impairment but impaired driving safety nonetheless. Conditions that inhibited either the effective operation of the vehicle controls or the ability to make sufficient observations when driving were felt to be significant. The VSG also described features of dementia that results in fatigue, daytime sleepiness, irritation, aggression that occurs towards early evening and progresses into the night time. This collection of features was referred to as 'sundowning'. Members of the VSG described these features of the condition as having a significant impact upon the person's ability to participate in functional tasks. An example of fatigue affecting driving was also well illustrated by a member of the SIG describing her father being involved in a collision, possibly as a result of falling asleep while driving.

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Both groups were eager therefore that the screening tool includes consideration of these physical elements.

Vision in relation to driving was a concern for both groups. Group members made the distinction between visual perception and a disturbance of visuospatial awareness and the visual acuity of the driver. Visual problems when driving were of particular concern during the hours of darkness when drivers reported having marked difficulties with the glare from oncoming vehicles. This problem relates to difficulties of contrast sensitivity which is defined as the ability of the eye to distinguish the differences between the luminance of two adjacent surfaces (Eek, 2015). In the absence of conditions such as cataracts and macular degeneration, contrast sensitivity is related to visual acuity (Van Rijn, 2005). Group members considered that the subject of vision and driving could not be satisfactorily assessed or addressed in the screening tool. It was therefore concluded that a brief explanation of the visual standard and advice would be included in the final document.

The members of the VSG made reference to the relationship between errors made driving and those occurring in other ADL tasks. Group members stated that in their experiences, similar error types occurred in performance of both tasks. Across the VSG, members described the development of patterns of errors occurring in a number of very familiar tasks. Errors did not occur consistently but were present intermittently. These errors related to the completion of tasks in the correct sequence and the failure to include all the components of the task. These sequencing and omission errors did not appear to be linked to the complexity or familiarity of the task. The level of conscious engagement in the task also did not appear to influence the presence of performance errors. These findings appear

to support research carried out in an analysis of the preservation of action based memory in people with a diagnosis of AD (Rusted and Sheppard, 2002).

6.3 The design of the driver with dementia pack:

The members of the SIG explored the probable design and format of the tool. A distinction was made between standardised assessment batteries and less formal screening tools. The SIG concluded that screening tools could involve the input of carers and the person with dementia.

It's a screening tool isn't it, more than a formal assessment? You have to be careful that everybody is doing it exactly the same way, that's the only problem. It's like the mini mental state. I've seen people doing one and I've thought what are you doing because then they get a high score then I go and do one and because they don't do it according to the guidance notes. It's only a screening tool though not a formal assessment. So yes I think they [family members] could do it. *Alan. SIG meeting 2, 150 – 158.*

The VSG also raised the issue of who would be the likely user or administrator of the screening tool. Members of the group were eager that the person with dementia and their family were given a more active role in their screening rather than simply be a passive subject of the screening process. Janice indicated that the screening tool, where ever possible, should be completed collaboratively.

Who's going to do this? Is it going to be the person with dementia or is it going to be the carer? Who's going to look at it? Because I was looking at it and wondering if both could do one? *Janice. VSG meeting 3, 315-320.*

Members of both the SIG and the VSG had very clear feelings about the manner in which the information should be presented. Through the group meeting process, the content and

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components were identified and agreed. The phrasing and tone of the language was considered to be extremely important. It was concluded that although the information contained in the final document should be clear and explicit in addressing the issue of driving cessation it should aim to deliver the information with sensitivity. The VSG were clear that the tone and language used to communicate information should seek to minimise the distinction between those providing and those receiving the information. The use of language in the information and screening tool was considered to be a key element of the success of the final document. Group members cautioned against using language overly laden with formality and medical terminology. A process of modifying the language used in the screening tool occurred as the development of the tool progressed.

Is there not a better way of putting that (sequencing)? Would you not need something like missing parts of tasks out? I'm just trying to make things simpler because not everybody may understand difficulties with "sequencing tasks".
Christine. VSG meeting 3, 387 - 391.

Janice. So, about how people perform in everyday activities – maybe we should write that. 'How do you perform in everyday activities?'

Brenda. What about – 'Are you able to manage such items like buttons?' *VSG meeting 4, 346 – 348.*

The SIG explored the value of a formal tool when monitoring driving during the course of the health professional's intervention. It was agreed that a screening tool sensitive to changes in driving would offer the opportunity to record and manage changes in the person's driving safety.

I think as far as the screening tool, it's not going to be a one-time event it's going to have to be repeated as people kind of change or deteriorate, doesn't it? Say like someone, an amputee, you could do an assessment, their legs not going to grow

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back. So, they're not going to change. That was meant to be a joke that. But people do change don't they? They deteriorate so, it's an ongoing assessment.
Alan. SIG meeting 1, 363 – 370.

Implications for the Screening Tool: Discussion

Both groups agreed that the administration of the tool should include the person with dementia, family members and health professionals. This decision reflected the spirit of collaboration that has been central to the research and development of the screening tool and information pack. The collaborative approach is also consistent with the theme of involving the person with dementia in evaluating, monitoring and managing driving status.

The accessibility of information was a significant consideration and material was amended to exclude jargon or overly clinical language. The VSG members were influential in the revision of phrasing throughout the development process of the information pack and screening tool. Guidance from the VSG regarding the design and presentation of the information included the style and size of the type face used and the use of a single column of text on the page. It was also recommended by the group that information should be presented logically and in small sections. This aim may not be entirely successful owing to the quantity and complexity of information that needed to be included. Direction from the Dementia Engagement and Empowerment Project Guide, (DEEP 2013) suggests the use of diagrams in conveying complex information. The VSG concluded however not to include a diagram illustrating the DVLA medical investigation process as this was considered excessively complex, and unnecessary. Direction from the Guide also indicated that the use of bold headings to sections, text boxes and bullet points are useful features to increase the accessibility of information presented.

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The members of the SIG explained that a facility to periodically evaluate and map the person's driving over the period of their care would provide a useful resource for health professionals in monitoring the driving. Repeated testing, particularly with the formal screening element of the tool, creates difficulties associated with familiarity and learning, possibly limiting the usefulness of the tool. Leivens et al (2007) proposed that the validity of data generated through retesting may be questioned owing to growing experience in both the tests contents and the testing process. The authors of the research point out however that problems with the retest effects are largely confined to cognitive tests and do not relate to achievement or knowledge tests. In fact, their research findings are similar to others such as Hamilton and Shuminsky (1990) that established that testing performance of those undertaking personality tests became more reliable during retesting. Moreover, for the driver screen, retesting would also involve the topic of driving being addressed periodically and offer a vehicle for the continuous collaborative monitoring and management of driving. The weaknesses of repeated screening may therefore be outweighed by the strengths of periodically retesting.

6.4 Themes not included in the Information Pack or Elements of the Screening Tool:

The approach of the research was to enable the groups involved in the research project to explore and agree the contents of the final prototype screening tool and information pack. Data generated from the group discussions were used to construct the contents and decisions regarding the inclusions were largely made by the group members. Data generated that was rejected for inclusion in the final document were few and related entirely to the practical driving assessment processes. Themes not included in the final study were 'lack of awareness of assessment processes', 'driving assessment process

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disadvantages older people', the use of driving simulators', 'Black Box technology', 'brain imaging in predicting driving safety', 'assessment in own vehicle', and 'assessments in own locality'. Members of the VSG were critical of the onerous nature of the current practical driving assessment processes and suggested a number of alternatives or improvements to practices.

The thing that I wondered about was the fact that you said that if somebody did the assessment then obviously they had somebody, an assessor, sat in the passenger seat and yourself sat in the back checking. Well, I know that if anyone did that with me I would be the worst driver in this world because I would be so nervous if somebody was at the back. I mean, you know, you're a really nice guy, but, you know, if somebody is there checking, it's your driving test all over again. *Brenda. VSG meeting 1, 251 – 257.*

Alternatives to the current practices were explored by the group members. Suggestions focussed upon approaches that included the use of technology and enabling people to be evaluated in a more familiar driving environment and when driving their own vehicles, VSG members suggested the use of "Black Box" technology that monitored driving performance. Group members concluded that although this type of technology would be useful in provide a more accurate description of the person's driving safety over a period it did not offer the type of information that would indicate deficiencies in driving owing to dementia, such as errors in visuospatial awareness or decision making. VSG members discussed the use of brain imaging to inform decisions regarding driving safety. The continued conviction that medical based technology and professionals might be equipped to provide information regarding driving safety was particularly interesting given that experiences of the group members with health care had been mixed.

6.5 Chapter Summary:

Chapter six has presented the data that contributed to the development of the screening element of the final document. It has described the themes emergent from group discussions that developed and shaped the content of the screening tool element of the final document. It has addressed decision making and driving risk and explored the strengths and weaknesses of data that can be used to indicate decrements in driving safety. These elements included formal screening, self reporting and family reporting. The VSG and SIG groups described their ways of knowing about the person's function and more specifically in relation to driving. It also indicated that a single source of information relating to a person's driving safety would be unlikely to be a sufficiently reliable indicator. The research findings concluded that personal and family reporting in conjunction with a brief screening tool would be most likely to offer valuable information relating to the person's driving status.

As in the previous chapter, this chapter has detailed and analysed the findings of the research groups involved in the study. It has described both groups' experiences, insights and development of ideas that have served to inform the construction of the information pack and screening tool. It has illustrated the source of the material and the manner in which the groups shaped the information contained within the final draft document. The next part of the thesis describes my development as a novice researcher and clinician working in the field of driving assessment as a consequence of involvement in this research project and by reflecting upon the process.

Chapter Seven: Reflexive Learning:

Chapter Introduction:

Chapter seven comprises reflexive information taken from personal accounts and reflective material that were recorded in journal form. Accounts relate not only to the research project and development of the screening tool but also include information from experiences from the research that has influenced my work in the clinical field. The chapter will explain the elements that influenced and contributed of the process of developing the driver screening tool and will also explore my personal development as a novice researcher. It will examine the practical and intellectual problems encountered during the research process and my responses and approaches taken that have shaped the research. It will provide an honest evaluation of the personal and political influences that have shaped and, on occasion, obstructed, delayed and diverted the journey. The reflections contained within this chapter are taken from journal accounts recorded during the entire process of the research with the concluding elements of the reflection contained in the final discussion/conclusion chapter of the thesis. As is customary this chapter will be written in the first person.

7.1 Selection of Research Topic:

The choice of the research topic arose from a desire to develop a meaningful driver screening tool specifically for use for people with dementia. Positivism and in particular the field of neuropsychology has directed the development of clinical testing tools in driving. The limitations of previous screening tools suggested that consideration be given to fresh approaches and ontological perspectives that were a departure from conventional understandings of knowledge. The willingness to break with convention and approach the

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development of the screening tool from a differing perspective should clearly be a response to the research question. The framing of the research question and approaches selected in answering the question were however, in no small part, prompted by my professional background. In appreciating the influence of occupational therapy upon the research approach, the development and philosophical foundations of the profession should be explained.

The Influence of a Profession

The philosophical background underpinning early occupational therapy practice was heavily influenced by Romanticism and more specifically the arts and craft movement. Romanticism was essentially a cultural movement driven by artists of different media and was most prominent in the mid 18th to 19th centuries. This movement emphasised the subjective, the individual experience, and nature (Hocking, 2008a). Ruskin (1964) and William Morris (1914) proposed that crafted objects were made precious by nature of the labour and attention given to it by its maker. Moreover, the act of creativity itself gave rise to pleasure, self value and self fulfilment (Hocking, 2008a). These concepts were in direct contrast to the values of Rationalism, medicine and the burgeoning industrialisation of the capitalist society of the time. These professional foundations and basic philosophical differences continue to be a source of ambivalence in acting both as an influence and discomfiture for current practicing occupational therapists in contemporary health care settings. Occupational therapy has found itself out of step with the dominant culture of positivism and responded both by promoting the value of its core principles while also adopting and applying the positivist principles to the practices of occupational therapy.

7.2 Development of the Research Project:

The process of designing the method of enquiry for the research has been both stimulating and challenging. The necessity for the research approach to fulfil the research aims and the requirements of the academic qualification was acknowledged but it was also important to me that the process and outcomes of the research had personal value and utility. The choice of research method has prompted a re-examination of occupational therapy's principles of creativity, subjective meaning and personal relationships that influence and share the fundamental elements of this research project. The intellectual freedom afforded by the research approach provided me with an opportunity to explore more imaginative solutions to challenges encountered at all stages during the process of the research.

Investment of time and endeavour in the development of the screening tool has been a personal source of creativity, inventiveness and pride and correspond entirely with the Romantic principles at the heart of the occupational therapy profession. Similarly, the emancipatory principles of participatory approaches to research were in keeping with the characteristics of personal development and fulfilment of romanticism.

The reflexive element illustrated the Freirian influence in the study that the research is, and must be, a two way process. The process of developing the research project has in turn resulted in a significant change in my professional practice and approach to work and responsibilities. It is apparent that developments within the study have unconsciously filtered into my professional practices. This has been manifest in changes in practices within the assessment centre and in my involvement in the national organising body.

My Position within the Study

As a practitioner with experience of working in the field of mental health and more specifically in the field of older mental health, working as a facilitator of a therapeutic group was a role I was comfortable with. The function of the research group however was not therapeutic in nature but was designed to be democratic and activity focused. For my own part in the study, I was anxious that my position within the group was not seen to be one entirely of professional expert but of joint investigator and collaborator. I intended that my contribution to the group would be viewed as research coordinator with specific expertise in the area of driving assessment but lacking direct knowledge of the experience of dementia. At the design stage of the study, I was uncertain of nature and level of contributions individuals would be able to make to the study but was confident that they possessed an expertise in living with the progressive and fluctuating condition of dementia. These reflections emphasised the feeling of relative inexperience in the role of researcher and, unhelpfully, intensified the responsibility I felt towards the groups to complete the research successfully.

I anticipated that although a degree of planning for the groups was required, the nature of group functioning would necessarily be unpredictable and the result of many spontaneous interactions taking place within groups. I therefore anticipated unexpected events that would need to be addressed in the moment and would define group member roles for the duration of the group meetings. One such event occurred during the initial meeting of both groups. Although it was made clear at the commencement of the group meetings that the focus of the meetings would be the personal experience of the group members in relation to driving, both groups took the opportunity to question me regarding dementia and driving and recount their often unsatisfactory experiences with dealing with the licensing

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authority and in receiving incorrect and inconsistent information regarding driving. This occurred in both the VSG and the SIG. During these meetings I considered asking that discussions return to the topic in view of the limited time available. I decided however that the only sincere means of addressing this would be to answer questions posed. I felt that owing to the democratic basis of the groups, members had decided that issues relating to licensing and driving assessment practices were important and therefore should be addressed. I was concerned that discussing these issues placed me in the undesirable role of professional expert and inhibited the planned functioning of the groups. On reflection however, I considered this to be a period where the groups perhaps used this issue not only to discuss licensing but also to discover more about me and my role. They also perhaps used this as an opportunity to become familiar and at ease with me as a group member. My concerns in the designing of the research relating to the group considering me as an expert appeared to be unfounded and after this period of questioning, the group cohesion appeared to progress well without inhibition. This event illustrated well my naivety which was perhaps borne out of a lack of experience in working with research groups and from an academic requirement to map the research process. It is possible that the group had used the only known connection available to them at that time, as a means of forming a relationship with me. It was perhaps not my interpersonal skills, the research method or my detailed planning of the research groups that ensured the success of the meetings but in fact, in the particular case of the VSG, it was the existing group's expertise regarding the practices and norms of group participation and their well developed skills of welcoming new members, that socialised me smoothly into their group.

Finally, in evaluating my position within the groups, I considered my direct and indirect influences upon the groups and the research process. I recognised that although my own

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wishes and needs would have a clear and direct bearing upon the progression of the study, other elements would also exert a degree of influence. These unseen elements included the university, the university ethics board and my employer who had provided some amount of funding. These agencies have, through a need to meet standards, regulations and expectations, exerted a degree of influence upon the design, structure and duration of the study.

Ownership, Leadership, Control and Power

I expected the interplay between ownership and control within the group to be vital in the outcome of the research. I was aware that group members were unfamiliar with the research topic and of the research process. I anticipated that both groups may expect my full direction and control of the project. This was a delicate element of the research design and resulted in risk taking and an immediate responsiveness towards the group's dynamic. On the one hand, it was reasonable for the group members to expect that I would direct the research project and a failure to do so might be interpreted as my lacking in the skills to conduct the research or that the research project was inadequately planned and of poor quality. Too much control and direction however, risked creating an oppressive setting in which the free discussion and sharing of experiences and ideas were likely to be inhibited. The collaborative nature of the study was made explicit and that a sharing of individual experience was an essential component of this research process. As part of the devolution of control, an outline of the aims of the research and a clear practical explanation for the research approach and rationale was provided. This was accepted by the group members who appeared ready to accept the more active role in the research design and welcomed a research project that placed significance upon their experience. Group members reported that they were excited by the research because it valued and directly utilised their own

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circumstances and experiences. This added to my sense of responsibility inasmuch as the research was no longer evidence of my own educative journey, but a vessel for the work and expectations for each of the group members involved. I was also keenly aware that the way in which control was negotiated and distributed should be sensitive to the group members to ensure excessive demands were not made in either an explicit or covert manner. From my experiences in the groups, particularly with the VSG, I concluded that although intimately connected, there is, I believe, a distinction between control, ownership and power within groups. It is possible for the group's purpose to be directed while all members feel an ownership and a significant degree influence within the group (Dixon 2000). The power assumed by the group members resulted from the existing maturity of the groups and also emerged from a development in the understanding and a gathering of expertise of the research topic resulting in a building of control amongst group members.

A Difficult Search for Honesty in my Research

My research reflected the desire for the experience of those people affected by dementia to be the material from which the screening tool was constructed. I anticipated that a crucial component of the success of the project would be the projects capacity to elicit the meaningful experiences of group members. The active collaboration of group members and the sharing of personal experiences in the research could not be taken for granted. The disclosure of information by members within the group demands that the data be valued, respected and treated with care. It also necessitated a reciprocation of honesty from all other members of the group and from me. This did not mean that members were obliged to disclose personal information but did require a degree of honesty of the membership of the group. For my part, I felt that the group members needed to be fully aware of my own wishes for the research, the external influences upon the study design and the completion

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of the study as part of an academic qualification. The authenticity of participation of group members was critical to the success of the groups and the outcome of the research and ultimately the efficacy of the final screening tool.

Science and Art

A prominent and recurrent theme of this research project has been the tension between positivism and interpretivism. The ontological approach of the research is a fundamental question for all researchers when planning research, but was particularly difficult to address in this research. It was imperative that the primary motive for selecting the approach was not entirely driven by my own needs and wishes or by being more secure with a particular ontological position, but that the research aim justified the means of enquiry. In carrying out the research and constructing the screening tool I have continually been confronted by the need to define and label the ontology of my actions and the resultant product. I have been compelled to consider whether the project has followed a qualitative or quantitative, positivist or interpretivist, scientific or intuitive. These labels are used not only to describe the ontological approach and in a broad sense the manner in which the research was carried out but is also used in some cases to quantify the value of the process and the resultant data. This point was particularly pertinent given that the tool will be employed in an environment dominated by positivism and scientific rigor. The desire to construct a tool that would be accepted in the professional environment of the intended users was an enticement that was consciously resisted when considering the research approach.

Craftsmanship

The process of conducting the research has included many components that have a familiarity. As discussed earlier this may be in part related to my professional background as an occupational therapist working in the field of driving assessment. It may also be related to my previous, but limited experience of group work and the research process. I do feel however that the act of generating a screening tool through a collaborative research process has a significant element of creativity and craft attributed to it. In discussions at the conclusion of meetings, members described an enjoyment derived from the discussions and a satisfaction resulting from the research developments. Group members explained that their active participation and input to the screening tool provided them with a sense of value and belonging to the group. The act of creating the information pack and screening tool was a deeply satisfying process for me as a group member. As an occupational therapist, I could not help but be struck by this aspect of the research and echoes with practice relating to meaningful activity giving rise to pleasure, self-value and self-fulfilment (Hocking, 2008a).

The approach of the researcher as interpreter, reflector and craftsman has been addressed by previous authors. Denzin and Lincoln (1994) describe the researcher as a bricoleur. Denzin and Lincoln illustrate the need for the qualitative researcher to adapt to circumstances and respond by finding the most appropriate solution to research design problems. Bricoleur, when used in these terms suggests that the qualitative researcher having a number of tools and skills at hand or a “Jack of all trades”. This interpretation of the word suggests a non-specialists or amateur workman. It suggests a worker with a broad skill set who does not possess a deep understanding of any aspect of their work. Crotty (1998) however takes a different view to this by introducing an element of artistry to the

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definition. This definition is drawn from the original Levi-Strauss text by Denzin and Lincoln in which the bricoleur is non self-reflexive and does not question whether they have the personal qualities or skills to complete the task, but rather is considers what may be constructed from the materials available to them. Using this definition, imagination and creativity are an essential in the successful completion of an activity. The worth of the results of the endeavour is therefore not judged by using the formal training and specialist experience of the researcher but by the creative approach and the elegance and functionality of the finished product. The creation of the final tool owes as much to crafting of the data as it does to a process of planning.

7.3 Chapter Summary:

This chapter has presented the elements of the research project that have prompted reflection and learning. Reflexive exploration of the process of completing the research has provided a number of insights that relate both to the process of the research but also to my clinical practice. It has also, perhaps unexpectedly, resulted in my ability to defend my choices in the approach taken. The reflexive process has been essential in forming an understanding of the influences that have had an unconscious bearing upon the research. This chapter has described in detail influences beyond ontological preferences and examined in detail the origins of the research project. The chapter illustrates the manner in which the philosophical underpinnings of occupational therapy have sensitised me to the approaches used in the development and process of the project.

The decision to dedicate a full chapter to the reflexive element of the study indicates its importance to my own development and its function in the development of the screening tool. The value of the reflexive process has provided a deeper understanding of the

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elements at work in forming the structure of the research and has permitted me to be secure in the justification of the research topic and the means selected to explore it. It has also performed a monitoring role throughout the stages of the research encouraging ongoing scrutiny of the process. Chapter Eight will explore further some of the key themes that have emerged from the research and examine the implications of the findings beyond the development of the screening tool.

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Chapter Introduction:

The first part of this final chapter will examine a number of broader themes emergent from the research and explore their implications beyond the boundaries of the research project.

A methodological critique of the research will then be provided that examines the process of completing the research and the value of the approach taken. The chapter details the study recommendations and outlines the plans in the continuing development of the screening tool. The final section of the chapter will present a concluding, post research, reflective account of the completed project.

8.1 Key Themes:

The thesis has outlined the issues relating to driving and dementia in the literature review and then described the development of the final tool through the collaborative process of the group meetings; the following section examines the themes that extend beyond the final screening tool.

Understandings of Dementia

Western culture's understanding of the diagnostic label of dementia is laden with a variety of meanings. The group organisation, processes and data produced by the VSG indicated that the group viewed themselves as outside mainstream healthcare and society. The group's purpose and rationale was to provide both practical guidance and emotional support from a position of shared understanding. The group's close relationship and identification of themselves as separate from formal care organisations was striking. The group members shared experience of dementia appeared more meaningful and had greater

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resonance to its membership than the understanding of dementia delivered by wider society. The group's high level of cohesiveness was perhaps not simply a result of the strong bonds created by shared experiences but was also perhaps a common defence against outside threat. Societal threats may have their origins in the perception that old age, illness and disability now have a dimension of self determination and therefore bring with them an element of blame (Lachman, 2006). Members of society are seen to have a duty to maintain themselves as productive contributors as opposed to unhealthy consumers of society's limited health resources. Rules related to health are propagated and maintained throughout all levels of society ensuring unthinking conformity in a manner similar to Foucault's microphysics of power (1975). This discourse has resulted in a 'health ethic', similar to that of the work ethic. Comparable to the work ethic, the health ethic is used as a gauge of personal strength or weakness and a marker of moral standing (Lupton, 1995). Contributing to this discourse is also the popular conception of control of health status and in particular dementia, through the pursuit of a particular lifestyle and/or dietary choices (BBC News, 2013). Strategies designed to manage driving and dementia must be designed within the social contexts in which they are intended to operate. The positive elements of self-determination and control should be emphasised and active collaboration with health and service providers facilitated.

The Distribution of Power

The element of power is an important issue for the person diagnosed with dementia. Challenges to personal autonomy are experienced through illness and disability. A sense of personal control has consistently been found to be associated with happiness, health status, financial security and an understanding of personal circumstances, or as described by Lachman, (2006) being, happy, healthy, wealthy and wise. For the members of the VSG

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all these factors were of direct relevance. All of the members of the VSG had retired from paid occupations and all attended the group owing to a diagnosis of dementia received by themselves or by a close family member. Members of the VSG described being at the margins of society owing to no longer feeling economically productive and self-sufficient and because of a lack of understanding and empathy regarding the condition of dementia. Powerlessness was also experienced in the relationships with health professionals and driving and driving cessation was one of the key topics over which these power differences were most obvious in this study. Actions of the person with dementia in relation to driving could be interpreted as risky and lacking in insight while conversely, interventions by health care professionals were occasionally viewed as hostile and lacking compassion by the person with dementia and their families. The data produced during the group meetings and the readiness of both groups to participate in the research suggests an enthusiasm and a willingness to improve the current position and to engage in a solution to the problems associated with driving.

Healthcare Responses to Driving and Dementia

The role of health professions in the area of dementia is also occasionally ambiguous. Members of the SIG described their function as both coordinator of care and interface between the person with dementia and health care services. Although all the members of the SIG agreed that driving and driving cessation was a recurring topic in their practice, differences in resolving this existed between members of the SIG. Addressing the difficulties with driving frequently resulted in conflict with the person with dementia and was incompatible with the health professional's customary role of promoting and maintaining independence and welling. The absence of pressing concerns with driving on first contact with their patients, coupled with an uncertainty of how dementia might affect

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driving, frequently resulted in driving briefly addressed or ignored entirely. Approaches towards the management of driving in dementia both from the experiences of the SIG and of the VSG suggested a lack of planning and preparation for the inevitable problems encountered as the dementia progresses. This appears to correspond with the research evidence discussed previously. Agreement about the role and responsibility of the health professional in the management of driving was not clear within the SIG and confusion regarding the health professional's duty of care was a significant theme. Paradoxically this uncertainty may offer richer opportunity for greater collaboration with the person with dementia, compared to other areas of healthcare where roles have been firmly established.

Evidence from the research groups indicates that the management of driving with dementia should commence at the earliest opportunity, preferably upon the point of diagnosis. All members of the SIG agreed that health professionals involved in the person's care ought to draw attention to the necessary action following diagnosis, such as informing the licensing agency. It is suggested that this should be extended to include more detailed information. Health professionals should be explicit from the outset that the cognitive and/or physical skills necessary for safe driving will deteriorate to a degree that will necessitate driving cessation. Reassurance should be offered however, that safe driving is entirely possible in the mild to moderate stages of dementia and that normal driving can include driving mistakes and errors. The person with dementia and their family members should be made aware of driving behaviours that may be associated with a decline in the condition. Early engagement with the person in the monitoring of driving and the planning and graded implementation of alternative transportation should be encouraged.

Roads to Empowerment

The significance of awareness of issues relating to driving for the person with dementia was a consistent theme throughout both group meetings. The VSG and SIG expressed the need for clear, accurate and dependable information. Both groups considered this to be critical in limiting difficulties associated with driving and essential in enabling the person to take a more active role in decisions about driving. Freire, (1972) described an absence of an awareness of the present and future condition as an oppression. The oppression experienced by many people with a dementia is one of powerlessness in relation to the health professionals and the licensing agency who have greater ownership of knowledge. A rebalance of this power, according to Freire, cannot be achieved by the liberality of the powerful but instead requires the active contribution of those experiencing the oppression. Viewed in these terms therefore, simply distributing information regarding driving will not be sufficient in rebalancing power between health professionals and those with dementia. Only an active and open involvement in matters from the point of diagnosis would enable people with dementia to become conscious of the effect of dementia upon driving and enable a positive participation in the management and planning process. This involvement should be structured as a positive collaboration between health professional and the person with dementia where the input of all persons involved are acknowledged and valued.

Practical barriers to collaborative actions included the time available to devote to driving by health professionals in their interventions, a limitation in the number of opportunities for face to face contact with the person with dementia, and the lack of understanding of the driving and dementia. It was clear from the group discussions and from previous research such as Gillespie et al, (1999) and Hawley et al, (2010) that health professionals are uncertain about the processes and effects of dementia upon driving safety. Insufficient

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understanding of the issues relating to driving can result in an avoidance of the subject because of the expectation of the person with dementia and even the health professional themselves to offer sound guidance and advice. (Freire, 1972).

Satisfactory Driving Cessation

An inescapable element of the development of dementia is that the condition will lead to a deterioration of cognition, sufficient to make driving unsafe. Achieving a satisfactory transition to driving cessation is the aim of any intervention. There was common agreement across the two research groups about what might be considered to be a satisfactory transition. Both groups were clear that the safety of the person and other road users was of paramount importance. Both groups also acknowledged that acceptance was a key element in outcomes that could be considered as satisfactory. Finally, the maintenance of social and functional activities, despite cessation, were considered to indicate a satisfactory transition. Interventions considered unsuccessful were those that were felt to be enforced, unexpected and unwarranted by the person with dementia. The implementation of an early collaborative intervention would ensure that people with a diagnosis of dementia were aware of the eventual need to cease driving, were integral in planning compensatory strategies for the time of driving cessation and cessation was a planned and graded process.

8.2 Implications of the Study:

Because the methodology used in this study questions realism, preferring instead to consider the multiple perspectives that are constructed and moderated by social factors, questions regarding the transferability of the findings must be addressed. In order to acquire legitimacy in generalising qualitative findings, qualitative studies have often

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included quantitative elements in the research design (Silverman, 2001). This approach was resisted in the design of this research project but rather focussed and drew upon the social processes of dementia and driving to provide utility. The premise of this approach is that similar generic social processes occur in a number of diverse social settings (Stoddart, 2004). From this it was concluded therefore that the experiences of the SIG and VSG groups are likely to have a wider relevance, beyond the settings in which they were generated (Mays and Pope, 2000). The active role played by those taking part in the project points to the value of research approaches that promote meaningful involvement and empower individuals to participate in the direction and outcomes of research. This study demonstrates powerfully the strengths offered by people with dementia to the research process. An important contribution of this research is the clear demonstration that the active participation of people with dementia can be an essential element in the successful outcome of research projects and central in correcting stereotypes and increasing the visibility of people with a diagnosis of dementia.

Driving with Dementia

The current means of evaluating fitness to drive for people with dementia does not have a formalised approach and relies heavily upon the experience of the health practitioner, the individual themselves and those closest to the person with dementia. General cognitive screening tools are often employed and inferences from the performance of these are used to evaluate possible decrements in driving safety. This research suggests that the use of self and family reporting combined with the person's performance in activities of daily living and cognitive screens may provide an accurate account of the person's functioning and driving safety over time. Additionally, the data from the research groups suggest that driving errors associated with dementia have a characteristic profile that is distinct from

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errors resulting from poor driving technique. Identification of these characteristic driving errors may enable people with dementia and those involved in their care to determine and plan management of safe driving and transition at an appropriate time to driving cessation.

Engagement

A significant theme of the research was the poor engagement in the issues related to driving for both health professionals and for those with a diagnosis of dementia. The value of early planning in the management of driving cessation was evident in this research project and has been demonstrated elsewhere (Musslewhite, 2011b). The barriers to this early planning are difficult to understand, ostensibly as both groups identified early planning as a useful approach and expressed a desire to incorporate this into existing practices. It is apparent however that a number of obstacles to developing an early management approach are inherent in the nature of the relationship of the person with dementia and those providing care and support. Data from the research groups illustrate health professionals having limited time to address driving and a lack of control owing to a limited ability to evaluate when driving has reached the point of being unsafe. Further to this, the act of being responsible for the removal of the person's entitlement to drive was a challenging issue for both the health professionals and carers of the person with dementia to address.

8.3 Methodological Critique:

The Use of Existing Groups in a Participatory Approach to the Research

The aims of this study were to utilise participatory research methods in the development of a driver screening tool for people with a diagnosis of dementia. The use of existing, mature and well-functioning groups greatly simplified the task of facilitating collaboration of the

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members of the research group in the research process. The formation of groups specifically for the purpose of this research project may not have yielded data of a similar quantity and quality in the time taken to carry out the research project. Members of both groups had established roles within the groups and accepted my introduction from a position of relative power. The participation of the groups in the research was entirely voluntary and was additional to the group's usual meetings. This placed the groups in a significantly more powerful position in the research than if formed for the purpose of the research. Evidence of this was the groups' actions in integrating me into the groups and the expansion and development of the original research aims by both groups.

The weaknesses of including existing groups in the research may have been that already established roles in the groups may have resulted in greater input from dominant members and limited the valuable contribution of some group members. Differences in contributions of members of both groups were identified. Efforts to draw group members into discussions were made, but not pursued owing to the possibility of memory and communication difficulties interfering with the social interactions. Contributions from all group members were however, made during the process of the research project. A further weakness in including established groups was that the project was perhaps more vulnerable to failing to meet the stated aims because of existing agendas. This was seen as a necessary weakness of using a participatory approach, where control of the project was not entirely in the hands of the researcher. In short, this weakness appeared to be an essential risk to take if the benefits of consenting participation and collaboration were to be enjoyed.

Was the Research Emancipatory? The Benefits of Involvement

In order to answer the question of whether the research contained an emancipatory element consideration needs to be given to what is understood by the term emancipatory research.

The designation of emancipatory research has been used in a number of research fields and covers a range of approaches. The essential tenets of emancipatory research have been described by Oliver (1992) as an approach facilitating a political awareness of the existing possibilities and a confronting of oppression at all levels. Oliver further suggests that emancipatory research is not primarily concerned with empowerment of people in the research process but how the research might further support wider societal empowerment (Oliver, 1992). Wallerstein and Duran, (2003) explain that those involved in emancipatory research should recognise issues of concern and their historical underpinnings. Research should then agree, through dialogue and involvement in social movements, what practices, social actions and modifications to discourse are open to change.

To suggest that this research achieved an emancipatory function for both groups involved would overstate its impact. Both research groups were functionally mature and, in the case of the VSG, socially active in dispelling myths and promoting a positive representation of living with dementia. Both groups were also effective in providing valuable support to their membership. Because of these factors therefore extensive emancipatory actions were not expected or achieved. That is not to say that emancipatory elements were not present in the research. Using feminist research as a foundation, Oliver (1992) proposed that emancipatory research incorporated three key elements. These were that for research to be considered emancipatory it should include reciprocity, gain and empowerment. The process of reciprocity was established in the design and was central to the success of the research project. The process of ongoing sharing of ideas and experiences served to

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develop, shape and create the screening tool. Similarly, in keeping with the principles of social citizenship, reciprocal exchanges also aimed to establish and maintain a sharing of power and engagement in the research. Gains for those involved in the research were perhaps limited to an increase in knowledge and a positive response to the collaboration in the development of the final draft tool. This knowledge however was no longer useful for many of the VSG as most had ceased driving. Gains for the members of the SIG however were perhaps more significant as new knowledge may be incorporated in their work role. Finally, direct empowerment resulting from involvement in the research is difficult to gauge. As previously discussed, most of the members of the VSG had reached the point of driving cessation and therefore personal empowerment related to issues of driving no longer held significance. This did not however mean that members of the VSG were not empowered by their involvement in the research. Exploration of the discourse of dementia was felt to be extremely helpful to members of the group in their understanding of the relationship between those with a diagnosis of dementia and wider society.

Collaborative Learning

Freire (1972) opposed the traditional expert and novice view of the educational process, instead advocating the practice of mutual education through exploration and mediation of the world. In a traditional relationship I may have been considered the expert in the field of driving with dementia, however in reality, my clinical expertise was actually of limited value to the progress of the research. The process of exploring and naming the world of driving with dementia was, I believe, educational for all members of the research groups and for me in particular. The establishment of the principle of collaboration in exploring the issues of driving was explained at the outset of the group meetings with both the SIG and the VSG.

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In keeping with the ontological principles of the research project my personal learning from involvement in the research groups should be acknowledged. I came to understand the dilemmas experienced by health professionals of when and how to address driving and that this often placed them at odds with the person with dementia. I learned that driving is usually poorly considered at the point of diagnosis and rises in prominence as the condition progresses. I also gained an understanding of the personal and practical implications of sudden and unexpected driving cessation. The difficulties for the close family members of the person with dementia were also a significant area of learning. The importance of the family member in managing and maintaining the process of driving cessation had not been clear previously. Similarly, the conflicts caused by this role and the personal guilt felt by the family member was an important aspect of the research findings. Finally, I gained a degree of understanding regarding the presentation of dementia and the progression of the symptoms such as visuospatial deficits and irritability and fatigue.

Although the principle of collaborative learning is laudable, it must be recognised that it also places greater demand upon the groups in respect of their active involvement and willingness to participate. It also asks that those involved explore what may be difficult issues without the support of a traditional educator/principal lead. Despite these potential threats, both groups quickly accepted the structure of the research and functioned productively acknowledging my lack of expertise in their world experiences.

Collaborating learning was achieved and the product of this served to develop the final draft of the screening and information pack.

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Representativeness

Although the representativeness of the research sample is not considered necessary or desirable in participatory action research, the composition of both research groups was largely female. It is unclear whether this impacted upon the data generated or whether groups with more male members would have provided different data. There is research suggesting differences in driving practices and experience between male and female drivers and travel pattern differences between genders (Rosenbloom, 1993). However, the patterns and reasons for ceasing driving after a reasonable driving history were very similar in both men and women drivers (Hakamies-Blomqvist and Siren, 2003). This suggests that the data collected in this research project would not have differed markedly because of the gender imbalance of the research groups.

Study Limitation: What I Might Have Done Differently

The process of conducting this study has presented a number of insights and periods of learning relating to the research and analysis process. These have occurred at all stages of the research process. Modifications to the research project resulting from learning and reflection upon completion of the research project are as follows:

Firstly, the involvement of the research groups at the planning stage would have enabled the aims to be more specific and focussed. This would have been in keeping with participatory action research and would have increased the participatory and ownership elements of the project. Although not practical in research completed in completion of an academic qualification, the expertise and experience of the SIG and of the VSG would have been valuable in the development and design of the research project.

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Secondly, the large proportion of the members of the VSG had been diagnosed with AD, although two of the group were carers for people with VaD. The members of the SIG had experience of a range of dementia types but a large proportion of the SIG were team members of memory clinics. This clearly resulted in many of the experiences explored being that of AD. It is not possible to determine whether this affected the data produced and in turn the development of the final draft of the tool. The involvement of people with a range of dementia types in further studies is essential in widening the breadth of the experiential input and relevance of the final tool.

Thirdly, the use of assistive technologies such as data analysis programmes would be useful in reducing the demands of the research process for the researcher working independently. Although the transcription and analysis of the data was a useful exercise in becoming familiar with the data which greatly assisted the data analysis process this was a particularly time consuming and demanding task. This was especially challenging when it was necessary to process data in a short time period for further meetings.

Finally, the circumstances under which the research project was completed, that is in completion of an academic qualification, resulted in the study including a number of constraints. These included it being time limited, the requirement of me to demonstrate knowledge and skills and therefore needing to retain a degree of control in the design, process and manner in which the outcomes were presented. I remain convinced of the value of participatory approaches in collaboratively producing information and tools for the evaluation of people with dementia. In particular, I am confident that the information produced by this study will greatly assist in the management of issues relating to driving and dementia. Studies of this kind that choose to utilise participatory methods should aim

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to enable the involvement of participants and avoid more tokenistic approaches to participation.

8.4 Recommendations Resulting from the Research:

Screening Tool Validation Study

The stated aims of utilising the experience and expertise of community health care and dementia support groups to develop a driver screening tool has been achieved. The final tool developed from this research project will however require a further validation study to evaluate its efficacy in identifying decrements in skills required for driving that are likely to make continued driving unsafe. This proposed research project would include people with a diagnosis of dementia referred to driving assessment centres for a practical driving assessment. It is anticipated that the study would be multi-centred and would seek to explore the levels of agreement between performances on the screening tool against performance in an on road assessment. Future research projects may look to explore the efficacy of the screening tool in relation to other conditions of impaired cognition such as brain injury and stroke.

Additional to this a further study is recommended to explore the value of early collaborative management of driving in dementia. This study will seek to investigate the importance of early information and collaborative management of continued driving for people newly diagnosed with dementia and whether this is useful in achieving satisfactory driving cessation. This study will be a small case study following the person from the point of diagnosis to driving cessation. The programme will be specifically designed to address driving with dementia and preparation for driving cessation. It will take account of personal and environmental circumstances and evaluate the progression from active driver to driving cessation.

Study Recommendations

These recommendations were emergent from the research data and relate to the individual experience and to wider personal mobility issues for people with dementia. It is important to note that although these were developed from the research groups, the recommendations were drafted after the completion of the research groups and were therefore not finalised with either of the research groups.

The Meanings of Dementia

The experiences of the person newly diagnosed with dementia should be acknowledged by those involved in their care and the meaning of the diagnosis negotiated. Existing perception of the condition should be explored with the person and their family members to explore understandings and limit the impact of negative stereotyping. With particular regard to driving, dialogue should be clear that many people manage to continue to drive but discussions should encompass all aspects of driving management and driving cessation.

The use of the Information Pack and Screening Tool

The information section of the screening tool is intended to be employed by health professionals to assist in the provision of consistent and reliable information to the person with dementia and their family members. The information contained within this section offers guidance while providing a focus for discussion and close collaboration between health professionals, family members and the person with dementia. The tool should be used to monitor performance and guide action of the person with dementia. It is designed to provide guidance throughout the process of driving with dementia and prepare the driver for the progressive transition to driving cessation. The screening element of the tool should

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be administered when concerns regarding continued driving are raised. Scoring of the tool will be dependent upon the outcomes of further studies designed to evaluate the efficacy of the screening tool.

Active Collaborations: The Person with Dementia

The findings of this research project reflect in a number of ways the value of social citizenship in the field of dementia. One element was the importance of meaningful participation of the person with dementia in addressing driving and value of planning for eventual driving cessation from the point of diagnosis. The person with dementia should be active in preparing strategies to replace driving in the performance of activities daily living. They should also actively participate with a close family members and/or health professionals in the monitoring of driving and contribute meaningfully in eventual decisions regarding driving safety.

Family Members

A number of recommendations for the family members of people with dementia can be made from the results of this study. Firstly, the active engagement and support of family members in the management and eventual cessation of driving is likely to result in a smoother transition and greater acceptance of driving cessation. Further, the use of an explicit family management and recording system, such as that contained in the information section of the tool, throughout the progression of the condition, would enable more structured monitoring of driving. This would enable decisions about driving safety to be based on first hand evidence gathered over the progression of the condition. The use of the information pack and screening tool will also increase family members' awareness and vigilance of the characteristic errors in driving that occur as a consequence of dementia.

Healthcare Services Role in Managing Driving with Dementia

Research findings from this project correspond with previous research findings that indicate that awareness and support provided by health professionals in driving for people with dementia was inconsistent. It is recommended therefore that healthcare services in dementia should recognise and include driving as one of the core elements of their interventions. Discussions regarding the impact of dementia upon driving should take place at the earliest opportunity, being clear that an eventual need to cease driving will result. Health professionals should adopt a collaborative approach to the monitoring and management of driving and should explore alternatives to personal vehicle use at an early stage of the intervention.

Community Services

Deficiencies in community services and a lack of awareness of alternatives to vehicle usage were themes of the research findings. The following recommendations are a result of experiences and suggestions made by members of the research groups. Firstly, development of existing community transport schemes to introduce people to using public transport who have recently been diagnosed with dementia is suggested. This may include an assisted traveller or ‘buddy’ scheme to accompany a person who has recently ceased driving. Secondly, is the inclusion of people with dementia in local authority taxi voucher schemes to assist people in bearing the financial cost of taking taxis. These schemes are typically available to people who have a disability limiting their physical mobility. Thirdly, people with dementia would benefit from improvements in the user friendliness of public transport information, such as simplified bus and rail information and timetables. Similarly, dementia friendly transportation technologies on public transport, such as information screens fitted to trains and buses detailing the next planned stop and the final

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destination of the journey, could ease the concerns and difficulties of people with dementia when using public transport. Finally, the promotion of strategies designed to replace vehicle usage should be promoted and cultivated. Examples of these include the formation of vehicle sharing schemes for people unable to continue driving should be encouraged in local communities. Financial grant assistance or lease schemes for obtaining a mobility scooter for those recently ceasing driving could be explored. The promotion of courses to enable people with dementia to learn basic computer and internet skills to facilitate access to online services is also a straightforward means of enabling greater access to services for people with dementia.

8.5 Post Research Reflections:

The process of reflection has been carried out throughout the course of the research project and described in a previous chapter. These reflections were written both prior to or during the process of undertaking the research. Reflections were recorded in a journal and then organised using a framework to give them a coherent structure. The framework on which to build the reflections was taken from Carper (1978). This framework has influenced the creation of specific reflective models, particularly Johns (1995) but I considered the rigid use of a formal model unsatisfactory owing to the breadth of reflective analysis. The framework was selected during the course of the research because of the relevance of the elements of the framework. It was important to conclude the narrative of the reflective element on the completion of the research project to describe the journey, experiences and learning acquired as a consequence of my involvement. In this reflective element, I will revisit a number of key elements addressed in the initial reflective section of the thesis.

Empirics: The Science of Researching Driving with Dementia

The naming and ownership of dementia by contemporary medicine has resulted in the investigation of dementia being dominated by positivism. Technological advances in investigative techniques continue to move age related cognitive impairments from the everyday to the pathological. There is now a perceptible gap in medical understandings of dementia and the lived experience of those with the condition. This disconnect was clear in the VSG who expressed discontent with medical interventions and disparity in the aims of health professionals and those with dementia. This disparity could be a product of expectations raised by the promise of scientific and technological advances or it might be that medical interventions have a more limited role in mild to moderate dementias. In either case, it was apparent that the needs of those with dementia and their family members relate to daily function and the acceptance of the condition.

Researchers investigating driving have continued to explore a means of psychometric measures that indicate when a person's driving has deteriorated to a level that renders it as unsafe. This modernist discourse is pervasive and was also expressed in both research groups who frequently questioned whether technology could be employed to monitor and resolve the problems of monitoring safe driving. This research intended to move away from this discourse and explore whether a divergent approach to the design of a screening tool would offer a more successful alternative.

Aesthetics: The Art of Researching Driving with Dementia

The researcher as a craftsman or bricoleur has been explored previously. The experience of conducting this research project illustrated the tension between science and art and between modernism and postmodernism very well. Qualitative research methods elicit

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scepticism regarding the value of the research. When discussing the project with colleague's sympathetic to qualitative approaches, I am conscious that use of the term 'artisan' or 'craftsman' is acceptable but discussion may not move too far towards to a creative approach, as this is likely to diminish the value of the product of the research in some way. This position however has its roots in the modernist construct that art is folly and science valuable. My choice of approach to this research was largely driven by an eagerness to approach the issue of driving safety differently. The knowledge that the efficacy of the final screening tool would be validated in a quantitative study engendered a degree of freedom in the manner the screening tool could be constructed. The creative elements of the research related to spontaneous interactions and responses to events that occurred within the group settings. The shaping of the information pack and screening tool emerged as a consequence of both groups action. This research was not the product of recipe or production line but resulted from crafted talk within the groups. The outcomes produced by research are therefore a bespoke representation of the interactions of both group's involvement.

Group Member or Benevolent Expert? My Place within the Group

My integration into both the research groups was managed entirely by the group membership. I had very little control and it was clear from both groups that they retained the option of my continued inclusion within the group. Although the SIG consisted of health professionals, a small number of which were fellow occupational therapists, very little difference existed in my role in both groups. I was somewhat surprised that although my primary work role is the assessment of driving safety, during the discussions relating to the experience of driving with dementia I had very little to contribute. This was perhaps because my experience relates to a single episode of assessing driving and therefore I have

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little experience of the issues that occur in the progression of the condition to the point of a driving assessment.

Personal Knowing: Experience and Learning

The experience of involvement in this research project has resulted in learning across the topic of driving with dementia and of the research process. An initial concern was that my knowledge and experience as an occupational therapist employed as a driving assessor would, in some way, interfere with my ability to participate within the groups without influencing their output. It was clear from an early stage however that I had very little knowledge of the experience of people with dementia leading up to and beyond driving cessation. It was apparent that my expertise was fairly narrow and centred upon the driving performance of people at the point of assessment. None of the VSG had attended the assessment centre to undertake a driving assessment. I learned of the poor understanding of people regarding dementia and driving and of the little guidance and support available for people experiencing difficulties. I also learned of the personal mourning people and their families felt for the sudden and unexpected loss of driving and that this was perhaps the first noticeable indication of the decline associated with the condition and the first indication of the impending dependence. It was clear that although health professionals involved in the care of people with dementia were anxious to address the issue of driving on many occasions this was impaired by a lack of clear understanding driving and an uncertainty of what actions were available to them.

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Ethics: People with Dementia

The potential vulnerability and changing capacity of people with dementia has made their inclusion in research more challenging for researchers. Difficulties regarding the opportunities for involvement in research balanced with the ethical obligation of researchers to prevent harm are challenging. It is incumbent upon researchers however to address and overcome these difficulties to ensure that people with dementia are represented and current research.

Members of the VSG explained that previous researchers had given little regard for the people in the group and treated them as a resource, giving nothing in return. Research approaches, especially when engaging people with dementia, should include some degree of participation or reciprocation. There is a clear need to encourage research in this area and also create and promote good practice guidance for researchers that would be valuable for ethics committees, dementia groups and researchers themselves to ensure that empowerment and risk can be adequately managed and monitored.

8.6 Concluding Comments:

This research project initially aimed to develop and create a screening tool to identify decrements in driving for people with a diagnosis of dementia. The research approach was intended to provide those involved in the research with a degree of control in the research process and this resulted in a shift in the research focus. It has produced detailed and unexpected insights into the experiences of people with dementia, their family members and healthcare professionals. The research approach enabled open dialogue between group members in order to express, negotiate and communicate their experience of dementia.

This research approach is justified because;

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Dialogue cannot occur between those who want to name the world and those who do not wish this naming – between those who deny others the right to speak their word and those whose right to speak has been denied them. Those who have been denied this primordial right to speak their word must first reclaim this right and prevent the continuation of this dehumanising aggression (Freire, 1972 P69).

My role within this research has not been one of expert but more as a member of the research groups involved in the study tasked with exploring the experience of driving with dementia. In this way, the naming of the world relating to driving and dementia could be explored and explained. It is perhaps unrealistic to suggest that healthcare interventions may fully adopt this approach when involved in care for the person with dementia, however benefits of an early collaborative relationship with all those involved with the person with dementia appears to be clear.

8.7 Chapter Summary:

This chapter has presented the broad themes that were present throughout the research process. I have argued that the social construction of dementia marginalises those with a diagnosis of dementia and ensures that the discourse describing dementia is one of loss of body, function and mind. The chapter described the means by which this discourse is maintained and explored the manner in which power is distributed and preserved. The responses of healthcare services and professionals to dementia and driving were also discussed. The discussion then progressed towards proposals of the ways in which the person with dementia may be empowered. These themes, although not entirely unexpected at the outset of the research process, were considerable in their importance and appeared to

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be consistent in many of the discussion topics of the research groups. A critique of the methodology was provided and improvements to the study design proposed. The recommendations of the study were outlined and organised in accordance with the findings of the research. Details of further research with a focus upon the validation of the screening tool and the development of collaborative, early interventions programmes were given. Finally, post research reflections were provided in relation to dementia and the completion of the research project.

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Appendices:

Appendices:

Appendix A: Example of Literature Synthesis Table

Appendices:

Appendix B: Screening Tools used in UK Driving Assessment

Screening Tool	Purpose	Composition	Country of Origin	Year of Publication
Rookwood Driving Battery	Assessment of cognitive functions required for driving. For use with all conditions with a cognitive element.	Comprises 12 sections that are designed to assess reasoning, spatial judgement, form constancy and attention.	United Kingdom	2009
ADReS	Older Driver screening tool.	Comprises Trail Making and Clock Drawing tests. Also includes evaluation of ROM, power and visual acuity.	United States	2003
Trail Making A & B	Assessment of attention and task switching.	Comprises two tests (A and B) A, requires connection of a series of numbered dot. B, requires connection of alternate numbers and letters.	United States	1944
Clock Drawing	Measure of visual-spatial organisation, orientation and executive function	Person required to draw a clock face on a blank sheet of paper.		1983 Sunderland et al.
Stroke Drivers Screening Tool	Driving safety following stroke	Comprises dot cancellation, Square matrices and Road Sign recognition.	United Kingdom	1996
DORA	Driving safety	Assessment comprises initial interview, medical history, medical screen, sensory assessment, physical assessment, and cognitive	United Kingdom/ Australia	2010

Appendices:

		assessment.		
4-C's	Older Drivers	Scored on four domains. 1, crash history, 2, family concerns, 3 clinical status 4,cognition	United States	2008
COTNAB	General cognitive assessment tool	Assessment tool covers four domains, visual perception, construction ability, sensory motor and ability to follow instruction.	United Kingdom	1986
Rivermead Perceptual Assessment Battery	General cognitive and perceptual assessment tool	Comprises 16 subtests designed to test visual perception.	United Kingdom	1986
MMSE	Screen for cognitive impairment.	Comprise 30 questions	United States	1975
Montreal Cognitive Assessment (MoCA)	Screen for cognitive impairment.	Comprise 30 questions	Montreal Canada	1996

Appendices:

Appendix C: Project Information Sheet

PROJECT INFORMATION SHEET

TITLE OF STUDY:

People with Dementia in the Driving Seat: A Participatory Approach to the Development of a Driver Risk Screening Tool.

NAME OF RESEARCHER: Barry Clift

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with me if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

What is the purpose of the study?

The purpose of this study is to develop with the help of people with experience of living with dementia a screening tool to help understand when someone might be having trouble driving. The research is being carried out as part of the Professional Doctorate in Health and Social Care at the University of Salford.

Why am I being invited to take part?

You are being asked to participate because you are already a member of a dementia support group. Your experience and knowledge will be important in helping develop the screening tool.

Information Sheet; Version Two; 23rd August 2011

Do I have to take part?

Appendices:

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form. If you chose to join the study you can still withdraw at any time.

What will happen to me if I take part?

This research will try to use knowledge and expertise of people with valuable experience of living with a diagnosis of dementia in developing a driving screening tool. You will already be a member of a support group. This research will make use of these groups in tackling the issue of driving with dementia through group meetings. Approximately 3 to 6 meetings will be arranged but this will be decided by group members. The frequency, time and duration of meetings will be decided by those taking part. Meetings times will be arranged to be as convenient as possible for group members. As a member of the group you will contribute and approve each part of the screening tool development. **You will be able to contribute as much or as little as you feel you would like to**

What do I have to do?

The underlying principle of this research is designed to provide a more active role for those taking part in the focus and role of the research. The aim of the research is the development of a screening tool to help decide when a person might have problems with driving safely. As a member of the group you will assist with the development of the driver screening tool. You will also approve each stage of the project as it progresses. Your involvement will contribute to the understanding of the ways in which dementia impacts upon driving.

What are the possible disadvantages and risks of taking part?

There are no physical risks to you when taking part in the study. *Your involvement in the project will not affect your driving licensing entitlement.*

What are the benefits of taking part?

There are no direct benefits of taking part in this study. It will however provide valuable information about how people with dementia resolve worries about continuing driving and can help health professionals to give accurate and useful advice in the future.

Appendices:

Will my taking part in this study be kept confidential?

All information collected about you during the course of this research will be kept strictly confidential. It must be stressed that information or contributions made during your involvement may still be used even if you chose to leave the study. Any information that leaves the group meetings will have your personal details removed so that you cannot be recognized from it.

If a scientific paper is written about the results your name and details will be removed completely.

Who is funding this study?

No funding has been sought to carry out this study.

Who has reviewed this study?

The University of Salford ethics committee has reviewed the study to ensure the study meets its ethical guidelines.

Please contact Barry Clift at the Wrightington Mobility Centre, Hall Lane, Appley Bridge, WN6 9EP if you require further information or telephone 01257 256409.

Thank you for taking the time to read this information sheet. You will be given a copy of this information sheet and the consent form if you wish to take part in the study.

Appendices:

Appendix D: Demographics of Research Groups

Volunteer Support Group:	
Gender:	Number
Female	10
Male	2
Age:	
40-50	2
50-60	2
60-70	3
70-80	4
80-90	1
Carer or Person with a Diagnosis of Dementia:	
Person with a Diagnosis of Dementia	2
Carer	9
Other	1
Carer Relationship:	
Spouse/Partner	6
Child of Person with Dementia	3
Time as a Group Member:	
0-1 year	5
1-2 years	4
2-3 years	1
>3 years	2

Appendices:

<i>Special Interest Group:</i>	
Gender:	Number
Female	6
Male	2
Age:	
20-30	1
30-40	1
40-50	3
50-60	3
Professional Background:	
Nursing	6
Occupational Therapy	2
Time as a Group Member:	
0-1 year	0
1-2 years	2
2-3 years	2
>3 years	4

Appendices:

Basic Group Rules

1. All information about members and discussions within the group should be kept confidential.
2. Members of the group should listen and support each other without criticising or making judgements.
3. Each member is respected and all persons are made to feel equal within the group.
4. Each member has an opportunity to speak if and when they wish.
5. Each member's situation and opinion is respected. What is right for one person may not be right for another.

Alzheimer's Disease International (2012)

Appendices:

Appendix F: Timelines of Project

Volunteer Support Group:

Meeting One – 4th September 2012

Meeting Two – 11th September 2012

Meeting Three – 18th September 2012

Meeting Four – 25th September 2012

Meeting Five – 12th March 2013

Meeting Six – Christmas Lunch/Closing Meeting/presentation of research 18th December 2013

Special Interest Group:

Meeting One – 25th May 2012

Meeting Two – 20th September 2012

Meeting Three – 18th July 2013

Meeting Four – Closing Meeting/presentation of research 14th November 2013

Appendices:

Appendix G: Ethical Approval Panel Submission:

Research Ethics Panel

Ethical Approval Form for Post-Graduates

Name of Student: Barry Clift

Name of Supervisor: Dr. Jackie Taylor and Christine Smith

School: Faculty of Health Social Care, School of Nursing

Course of study: Professional Doctorate in Health and Social Care

Name of Research Council or other funding organisation (if applicable):

1a. Title of proposed research project

People with Dementia in the Driving Seat: A Participatory Approach to the Development of a Driver Risk Screening Tool.

1b. Is this Project Purely literature based?

NO (delete as appropriate)

2. Project focus

The project will seek to develop a screening tool for use in identifying decrements in driving skills in individuals with a diagnosis of dementia.

Appendices:

3. Project objectives

- To develop, in collaboration with dementia support group members and health professional groups, a prototype screening tool aimed at identifying the level of risk in driving.
- To identify existing dementia support groups and health professional groups prepared to collaborate with the researcher in designing the screening tool.
- To employ an effective method of collaborative working with the research groups.

4. Research strategy

(For example, outline of research methodology, what information/data collection strategies will you use, where will you recruit participants and what approach you intend to take to the analysis of information / data generated)

Research Method:

This project will be based on the principles of Community Based Participatory Research (Minkler and Wallerstein 2003). A variety of participatory approaches to research enquiry exist. Broadly, participatory approaches advocate the active involvement of individuals to varying degrees in the research process. These approaches range from projects designed to bring together a collection of stakeholders to address a specific topic to fully collaborative enquiries that negotiate and agree the entirety of the process from defining the area of enquiry to the dissemination of the findings. Participatory research aims to rebalance power in the research process through active participant involvement (Minkler and Wallerstein 2003). Evidence suggests that active empowerment in the research process not only increases the relevance of the process and the outcome but also creates practical benefits for those taking part (Alexander 2010). Community Based Participatory Research has been increasingly used in the field of public health, nursing and social work with the aim of integrating knowledge with interventions and policy change (Israel et al 2005). It has been used specifically in the health care setting with the aim of improving community health and eliminating health disparities. The value of patient and carer

Appendices:

involvement in healthcare research has more recently been recognised both within the delivery of healthcare and in health service policy making. The significant structural changes within the NHS, proposed in July 2010, lay particular emphasis on patient involvement and shared decision making in healthcare provision. (National Institute for Health Research 2010; Department of Health 2010).

This project will centre upon two separate community groups based in the North West of England. One group will consist of members of a dementia support group and the second group will comprise clinicians involved in the delivery of care for individuals affected by dementia. Group numbers will be decided in part by existing group membership and by the number of group members wishing to take part in the research project. It will however be made clear that groups will necessarily have a lower threshold of 4 members and an upper threshold of 12 members. These group sizes reflect the optimum numbers for groups, making group-work manageable for a single researcher (Tang and Davies 1995). Once formed, groups will direct the terms and conditions of group membership and agree the research processes to be adopted. Although Community Based Participatory approaches advocate full involvement of groups it acknowledges that the demands of the research process may overburden those taking part. For this reason groups engaged in the research project will adopt a consultative role (Stoecker 2001). The primary aim of creating a driver screening tool will be introduced by the researcher at the commencement of the project. Thereafter, groups involved in the research will provide input and approve each stage of the research process before progressing to the next stage (Beckwith 1996). The development of the screening tool and duration of the researcher's involvement with the communities will be over a 12 month period. This rigid time deadline is directed by the need to complete the primary aim of study in completion of an academic qualification. The frequency, duration and timetabling of community meetings will be decided by the community groups, however it is anticipated that a minimum number of 10 meetings will be required to achieve the primary research aim. The researcher will make explicit his involvement in both groups and groups will be offered the option to remain separate, communicate with each other or merge.

The research design is intended to promote the individual's participation in the research process and utilise the group's particular expertise. The approach rejects the conventional "expert professional" in leading the research and recognises the value of individual contributions, constructed meanings and group experience. It is anticipated that these collaborations

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will result in a driver screening tool that is sensitive to increases in driving risk while being practically useful.

The validation of the screening tool when completed will be addressed in a separate study and will not be included in this project.

Data Collection and Data Analysis:

Data gathering will be carried out by the researcher during opening meetings of the two separate groups involved in the research. Initially groups will be introduced to the research aim and an explanation of current screening tools provided. Open dialogue regarding the content and development of the prototype screening tool will be led by the researcher. Key discussions regarding the experience of the relationship between functional performance and driving in individuals with dementia will be initiated. Owing to the research being carried out by a single researcher all group meetings will be audio recorded to ensure all conversational data is recorded. These data will be transcribed by the researcher. The research design is intended to promote participation in the research process and utilise the groups' experiences and expertise. The groups will agree and select the most appropriate data gathering and analysis tools following discussions with the researcher. Group members may wish to employ data gathering strategies such as the Delphi process, structured or semi-structured interviews, and questionnaires. This would be done with the guidance of the researcher. The group may also widen the data collection to include other support group members not directly involved in the study. Data analysis strategies appropriate to the chosen method will be employed by the researcher. Care will be taken to ensure that the analysis of data is primarily carried out by the researcher in close collaboration with the group. This is considered necessary as data will need to be held and stored securely by the researcher. It is also vital that involvement in tasks is closely monitored to ensure excessive demands are not placed upon group members. Owing to the difficulty of removing or excluding data from the study, it will be made clear prior to commencing the study that all data collected during the course of the study may still be included in the research. This will include data collected from individuals who chose to withdraw from the study prior to completion of the project. Data analysis software such as Atlas/ti or Nudist will be used in the analysis of the data as required.

References:

Appendices:

Alexander I.M. (2010) Emancipatory Actions Displayed by Multi-Ethnic Women: "Regaining Control of My Health Care" *Journal of American Academy of Nurse Practitioners* 22: 602-611.

Beckwith, D (1996) Ten Ways to Work Together: an Organizer's View. *Sociological Imagination*, 33: 2
<http://commorg.utoledo.edu/si/sihome.htm> (accessed 19th March 2011)

Minkler, M and Wallerstein N (2003) *Community –Based Participatory Research for Health*. Jossey Bass San Francisco.

National Institute for Health Research (2010). The Way Forward: Making a Difference in Research by Actively Involving People.
<http://www.cmcc.nihr.ac.uk/OneStopCMS/Core/CrawlerResourceServer.aspx?resource=0a7b8fd649064f9798753b88fbf32dbd&mode=link&quid=fc04f3b83a5b46069682d44f2e86290c> (Accessed 11th February 2011)

Stoecker R. (2006). Why Don't We Do More Participatory Research? Key note Address Prepared for Creating Knowledge and Building Community. The First CSU Conference on Community Based Teaching and Research:
<http://comm-org.wisc.edu/drafts/pr.htm>. Accessed 19th March 2011.

Tang, K. Davies, A, (1995) Critical Factors in the Determination of Focus Group Sizes: *Family Practice*: 12 (4) 474-475

5. What is the rationale which led to this project?

(For example, previous work – give references where appropriate. Any seminal works must be cited)

Screening tools are designed to detect the presence or absence of a particular factor or to include or exclude a condition (Inwood 2007). Tools designed to evaluate behaviours vary in their ability to act as reliable predictors. The development of a driver screening tool that is reliable, valid, evidenced based and practically useful has so far proved elusive (McCarthy and Mann 2007; Kortling and Kaptein 1996). A review of driving assessment services carried out by Inwood on behalf of the Transport Research Laboratories (2007) discovered a disparity in the manner in which tests were administered and a lack of agreement regarding their value among assessors. The report discovered a widespread lack of confidence in the reliability of the tests in relation to the driving task. Doubts relating to the efficacy of these tests were expressed when attempting to evaluate cognitive status and more precisely driving performance owing to variations in an individual's performance capacity (Inwood 2007). Salthouse (2007) in a large scale study administered 16 cognitive tests on three separate occasions and

found wide variation in test performance results over a relatively short period. Salthouse's findings raise important questions relating to these types of assessments when based upon a single measure. They also emphasise the difficulties of identifying true changes from short term fluctuations and underline the need for evaluation tools to capture a more representative picture of an individual's level of function over time.

Many of the component skills employed in driving are necessary in the performance of daily living activities. Physical elements such as trunk stability, strength, exercise tolerance, and coordination are required in many aspects of daily function and are vital in safe driving (Staplin et al 1998). Similarly, limitations in range of movement of lower and upper limbs and of neck movement in older drivers are considered to be a contributory factor in older driver vehicle collisions (Koepsell et al 1994; Parsonson et al 1997; Meyer 2004). High correlations between an increase in falls (Forrest et al 1997) and difficulties in raising arms above shoulder level (Hu et al 1998) and vehicle collisions have been reported. Decrements in cognitive function have also been found to have a significant impact upon performance of activities of daily living tasks. Oakley et al (1992) reported an inverse relationship between a group of daily living activities and severity of the dementia. More specifically, Giovenetti et al (2002) identified that omissions or failures in accomplishing discrete components of an activity were the most frequent type of error made by individuals with dementia. Task component omissions were also most strongly associated with carer complaints relating to deterioration in everyday functioning (Brennan et al 2009). The findings of the relationship between task omissions and cognitive decline is consistent with the resource theory of action impairment. Resource theory was proposed by Schwartz et al (1998) who consistently observed high rates of omission errors in individuals with a moderate to severe cognitive impairment. By contrast individuals with a mild cognitive decline were observed to make omission errors in only the most complex and demanding daily tasks. Schwartz concluded that errors in everyday task performance resulted from limitations in cognitive resources and in the level of complexity and demand placed upon the individual by the task. To date very few tools include the physical and visual elements of driving. None of the screening tools used in the United Kingdom consider the use of functional performance in daily tasks as an indicator of driving capacity. The development of a driver screening tool with a focus upon daily activity performance may offer a more comprehensive and accurate indication of an individual's capacity in relation to driving.

Appendices:

References:

Brennan, L., Giovannetti, T, Libon, D., Bettcher, B, M., Duey, K., (2009) the impact of goal cues on everyday action performance in dementia. *Neuropsychological Rehabilitation*. 19, (4) 562-582.

Giovannetti, T, Libdon, D,J., Buxbaum L,J., Schwartz, M,F., (2002). Naturalistic action impairments in dementia. *Neuropsychologia*, 20, 1220-1232

Hu, M.-H., Hsu, S.-S., Yip, P.-K., Jeng, J.-S. & Wang, Y.-H. (2010). Early and intensive rehabilitation predicts good functional outcomes in patients admitted to the stroke intensive care unit. *Disability & Rehabilitation*, 32, 1251-1259

Inwood C (2007) Feasibility of Measuring Consistency of Assessment Outcomes Across the Forum of Mobility Centres. Transport research Laboratories. Unpublished Project Report UPR/SSI/019/06.

Korteling, J. E. & Kaptein, N. A. (1996). Neuropsychological driving fitness tests for brain-damaged subjects. *Archives of Physical Medicine and Rehabilitation*, 77, 138-146.

Koepsell, T.D., Wolf, M.E., McClosley, L. Butcher, D.M., Louie, D., Wagner, E.H, Thompson, R.S., (1994) Medical conditions and Motor vehicle collisions injuries in older adults. *Journal of the American Geriatric Society* 42, 695-700

Korteling, J. E. & Kaptein, N. A. (1996). Neuropsychological driving fitness tests for brain-damaged subjects. *Archives of Physical Medicine and Rehabilitation*, 77, 138-146.

McCarthy D, Mann W (2006) Sensitivity and Specificity of the Driving-Related Skills Older Driver Screening Tool. *Topics in Geriatric Rehabilitation* 22 (2) 139-152

Oakley F, Sherry L, Phillips D, James D, Ebner The Daily Living Questionnaire: A Functional Assessment for People with Alzheimer's Disease. *Physical and Occupational Therapy in Geriatrics* Vol 10, (2).

Sathouse, T. A. (2007). Implications of within-person variability in cognitive and neuropsychological functioning for the interpretation of change. *Neuropsychology*, 21, 401-411.

Staplin, L. & Dinh-Zarr, T. B. (2006). Promoting Rehabilitation of Safe Driving Abilities Through Computer-based Clinical and Personal Screening Techniques. *Topics in Geriatric Rehabilitation*, 22, 129-138.

Schwartz, M.F., Montgomery, M,W., Buxbaum, L,J., Lee, S., Carew T,G., Coslett, H,B., Ferraro, M., Fitzpatrick-Desalme, E., Hart, T., Mayer, N,H., (1998) Naturalistic action impairment in closed head injury. *Neuropsychology* 12, 13-28.

6. If you are going to work within a particular organisation do they have their own procedures for gaining ethical approval

(For example, within a hospital or health centre?)

Appendices:

NO (delete as appropriate)

If YES – what are these and how will you ensure you meet their requirements?

NHS National Research Ethical Service approval will not be required as both groups involved in the research have not been identified from services for which the UK Health Departments are directly responsible. The health professional support group is a voluntary group and is not associated with any UK Health Department. The research will not involve intrusive procedures with individuals who lack capacity to provide consent for themselves and will not include access to or the processing of confidential information outside the group without consent (NRES 2011). Individuals invited to take part will undertake a consultative role and will not be considered to be subjects/participants in the research project. Owing to the active nature of involvement in the research, NHS ethical approval for the groups is not required for the study (Involve 2009).

References:

Involve: (2009) Patient and Public Involvement in Research and Research Ethics Committee Review. National Patient Safety Agency. National Research Ethics Service. http://www.invo.org.uk/pdfs/involve_nresfinalstatement310309.pdf, Accessed 19th April 2011

NHS National Research Ethics Committee (2011) Does My project require review by a research ethics committee? <http://www.nres.npsa.nhs.uk/applications/approval-requirements/ethical-review-requirements/> Accessed 23/08/2011.

7. Are you going to approach individuals to be involved in your research?

YES (delete as appropriate)

If YES – please think about key issues – for example, how you will recruit people? How you will deal with issues of confidentiality / anonymity? Then make notes that cover the key issues linked to your study

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Project Recruitment:

The groups included in the study will be selected purposively by the researcher from existing community dementia support groups and from a peer support group comprising health professionals throughout the North West of England. The community support groups will include individuals with a diagnosis of dementia and their carers. It is anticipated that the expertise and experiences of each of groups offers considerable value in the design and development of the screening tool. Contributions from these groups will inform and guide the construction of part of the tool. Meetings will be arranged with the groups and an explanation and outline of the study and the study aims will be provided by means of power point presentation and informal discussions. Written information outlining the research project will be provided to prospective groups. Information literature will detail the purpose, method and duration of the study. It will explain the participatory nature of the study design but will emphasise that groups are able to contribute as much or as little they feel able. Group members will be contacted after a period no shorter than 24 hours to confirm their decisions to take part in the study.

8. More specifically, how will you ensure you gain informed consent from anyone involved in the study?

Consent:

The project will only include those able to grant full informed consent and will pay particular attention to obtaining the consent of those taking part. Informed consent has particular relevance when involving people with a diagnosis of dementia. Details of the study aims and research practices will be provided to each of the groups involved in the project. Information will include details relating to confidentiality, withdrawal from the study and protection of those taking part. It will also explain the participatory nature of the study design and emphasise that groups are able to contribute as much or as little they feel able. Because of the participatory nature of the project the issue of withdrawal will be emphasised. It will be made explicitly clear that individuals will be able to withdraw from the project at any time without obligation (Alzheimer's Society 2010). Information literature will include the name and contact details of the researcher.

References:

Alzheimer's Society (2010) Volunteering for Research into Dementia;
http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=151 (accessed 19th March 2011)

Appendices:

9. How are you going to address any Data Protection issues?

See notes for guidance which outline minimum standards for meeting Data Protection issues

Confidentiality and Data Protection:

Meetings with the groups will be audio recorded and transcribed in full. All transcribed data will be anonymised. These data will be stored in researcher's place of work in a lockable office. Research data will be stored locked filing cabinets and in password protected files on password protected computers. These data will be accessible by the researcher only. Additionally, the personal details and circumstances of the individuals within the groups will not be disclosed to parties outside of the individual's particular group.

10. Are there any other ethical issues that need to be considered? For example - research on animals or research involving people under the age of 18.

ETHICAL COMPONENT:

Demands of the Study:

Although setting the researcher a number of serious challenges it is essential that individuals with a diagnosis of dementia are given the opportunity to participate in the research process. To ensure rights are respected and dignity maintained, full consideration of ethical practice will be given in the design, involvement, undertaking and the reporting of the research project (C.O.T 2010). The research approach has been selected because it actively encourages autonomy of the individual within the research process and acknowledges the skills, expertise and contributions of those taking part. This approach does however contain its own ethical frailties. Green (2004) draws attention to areas of concerns associated with participatory approaches. Green's primary concern relates to the degree to

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which groups participate in the research, pointing out that too many demands can be detrimental while too little renders the project artificial. This project will take account of the demands placed upon the groups and the level of participation will be carefully modified by the researcher. Groups involved in the project will adopt a consultative role only (Stoecker 2001). Individuals taking part in the study will be continually monitored to ensure their role in the project does not become purely token or excessively demanding.

Risk to research consultants

The physical risk to individuals taking part in the study is considered minimal as no direct interventions will be administered. It is anticipated that the primary threat to those taking part in the project will be one of overburdening. Group members will be consulted regarding the project aims and agreement relating to the level of involvement will be established. Owing to the degenerative nature of dementia, consistent and continued monitoring of the level of involvement will be carried out throughout the project by the researcher at group meetings.

References:

C.O.T (2010). Code of Ethics and Professional Conduct Revised Edition, London College of Occupational Therapists LTD.

Green L, (2004) Ethics and Community Based Participatory Research: Commentary on Minkler. Health Education and Behaviour 31. 6 698-701

Stoecker R. (2006). Why Don't We Do More Participatory Research? Key note Address Prepared for Creating Knowledge and Building Community. The First CSU Conference on Community Based Teaching and Research: <http://comm-org.wisc.edu/drafts/pr.htm>. Accessed 19th March 2011

11. (a) Does the project involve the use of ionising or other type of “radiation”

NO

(b) Is the use of radiation in this project over and above what would normally be expected (for example) in diagnostic imaging?

NO

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(c) Does the project require the use of hazardous substances?

NO

(d) Does the project carry any risk of injury to the participants?

NO

(e) Does the project require participants to answer questions that may cause disquiet / or upset to them?

NO

If the answer to any of the questions 11(a)-(e) is YES, a risk assessment of the project is required and must be submitted with your application.

**12. How many subjects will be recruited/involved in the study/research?
What is the rationale behind this number?**

Group numbers will be decided in part by existing community group membership and by the number of group members wishing to take part in the research project. It will however be made clear that groups will necessarily have a lower threshold of 4 members and an upper threshold of 12 members. These group sizes reflect the optimum numbers for groups as suggested making group-work manageable for a single researcher (Tang and Davies 1995).

References:

Tang, K. Davies, A, (1995) Critical Factors in the Determination of Focus Group Sizes: Family Practice: 12 (4) 474-475

13. Please state which code of ethics has guided your approach (e.g. from Research Council, Professional Body etc).

Please note that in submitting this form you are confirming that you will comply with the requirements of this code. If not applicable please explain why.

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Code of ethics and professional conduct published by the College of Occupational Therapists.

College of Occupational Therapists (2010). Code of Ethics and Professional Conduct, Revised Edition, London College of Occupational Therapists LTD.

Remember that informed consent from research participants is crucial, therefore all documentation must use language that is readily understood by the target audience.

Projects that involve NHS patients, patients' records or NHS staff, will require ethical approval by the appropriate NHS Research Ethics Committee. The University Research Ethics Panel will require written confirmation that such approval has been granted. Where a project forms part of a larger, already approved, project, the approving REC should be informed about, and approve, the use of an additional co-researcher.

I certify that the above information is, to the best of my knowledge, accurate and correct. I understand the need to ensure I undertake my research in a manner that reflects good principles of ethical research practice.

Signed by Student _____

Print Name _____

Date _____

In signing this form I confirm that I have read and agreed the contents with the student.

Signed by Supervisor _____

Print Name _____

Appendices:

Date

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**Research Ethics Panel:
Application Checklist**

Ref No: <u>Office Use Only</u>

<u>Name of Applicant: Barry Clift</u>
Title of Project: People with Dementia in the Driving Seat: A Participatory

The checklist below helps you to ensure that you have all the supporting documentation submitted with your ethics application form. This information is necessary for the Panel to be able to review and approve your application. Please complete the relevant boxes to indicate whether a document is enclosed and where appropriate identifying the date and version number allocated to the specific document (*in the header / footer*), Extra boxes can be added to the list if necessary.

Document	Enclosed?		Date	Version No
	(indicate appropriate response)			
Application Form	<u>Mandatory</u>		If not required please give a reason	
Risk Assessment Form		Not required for this project		
Participant Invitation Letter		Not required for this project		
Participant Information Sheet	Yes		12/07/2011	1
Participant Consent Form	Yes		12/07/2011	1
Participant Recruitment Material –		Not required	Not used in the study	

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e.g. copies of posters, newspaper adverts, website, emails			for this project			
Organisation Management Consent / Agreement Letter			Not required for this project	.		
Research Instrument – e.g. questionnaire			Not required for this project	Not used in study.		
Draft Interview Guide			Not required for this project			
National Research Ethics Committee consent			Not required for this project			

Note: If the appropriate documents are not submitted with the application form then the application will be returned directly to the applicant and will need to be resubmitted at a later date thus delaying the approval process

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Appendix H: Evaluation of Capacity

Capacity has been defined as being a combination of four key components (Grisso & Applebaum 1998). These components include understanding, appreciation, choice and reasoning (Karlawish 2008). This instrument was originally designed to evaluate an older adult's capacity to participate in randomised controlled trials (Cacchione 2011). The scale consists of five items designed to evaluate the persons understanding of the project and implications for their participation. The instrument requires the individual explain their understanding of their role and asks what they would do if they became upset or wished to leave the study. These items enable the researcher to evaluate the individual's capacity with specific reference to the four key components. The tools can be administered informally in discussions and also can be used to carry out ongoing evaluations of capacity.

Evaluation to Sign an Informed Consent Document for Research

Subject Identifier: _____ Date of Evaluation: _____

Directions

Make a subjective judgment regarding item 1. Ask the subject questions 2-5 and record responses. The evaluator may use different wording in asking the questions in order to assist the subject's understanding.

1. Is the subject alert and able to communicate with the examiner? Yes _ No ____

2. Ask the subject to name at least two potential risks of participating in the study.

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3. Ask the subject to name at least two things that he/she will be expected to do during the study.

4. Ask the subject to explain what he/she would do if he/she no longer wanted to participate in the study.

5. Ask the subject to explain what he/she would do if he/she experienced distress or discomfort during the study.

Evaluator's Signature

It is my opinion that the subject is alert, able to communicate, and gave acceptable answers to the questions above.

Evaluator's Signature

Date

Appendices:

Appendix I: Consent Form

CONSENT FORM

Title of Project:

People with Dementia in the Driving Seat: A Participatory Approach to the Development of a Driver Risk Screening Tool.

Name of Researcher: Barry Clift

Group Membership:

Please initial box

I confirm that I have read and understood the information sheet dated 1st February 2012 (version...3...) for the above study and have had the opportunity to ask questions.

I understand that my involvement in the research is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected.

I agree to take part of the above study

Name of person taking part

Date

Signature

Researcher

Date

Signature

Copy to be retained by person taking part and by researcher

Appendices:

Appendix J: 'Thoughts Wall'



Appendices:

Appendix K: Final Tool

Appendices:

Appendix L: presentations and Seminars:

Presentations to Peers:

Clift, B. 'Driving and Dementia' Oral presentation to Warrington Memory Services 8th September 2014.

Clift, B. 'Cognitive Testing and Driving Assessment Process'. Oral presentation to The Forum of Mobility Centres' Annual General Meeting, 19th June 2014.

Clift, B. 'People with Dementia in the Driving Seat: Using a Participatory Approach to Research in the Development of a Driver Screening Tool' Oral presentation to Bridgewater Community Healthcare NHS Trust Research and Development Steering Group. 7th May 2014.

Clift, B. 'Driving and Dementia' Oral Presentation to Meadows Memory Assessment Services. 5th March 2014.

Clift, B. 'Cognitive Function and Driving Assessment'. Oral presentation to North West ST4-6 and Specialists Registrars Training Programme. 30th January 2013.

Clift, B. 'Power and Therapeutic Relationships' Oral presentation to the forum of Mobility Centres Education Programme. November 2012.

Clift, B. 'Consent and Confidentiality' Oral presentation to the forum of Mobility Centres Education Programme. November 2012.

Seminars:

Clift, B. 'People with Dementia in the Driving Seat: Using a Participatory Approach to Research in the Development of a Driver Screening Tool'. Oral presentation at the Bridgewater Community Healthcare NHS Trust's Clinical Audit and Research Symposium. 18th September 2014. Warrington.

Appendices:

Clift, B. People with Dementia in the Driving Seat: Using a Participatory Approach to Research in the Development of a Driver Screening Tool. Oral presentation. The University of Salford, Spring Symposium. 6th March 2014. Salford.

Clift, B. 'Using a Participatory approach in the Development of a Driver Screening Tool'. Oral presentation. College of Occupational Therapists 37th Annual Conference and Exhibition. 20th June 2013. Glasgow.

Clift, B. 'Cognitive Testing and Driving Assessment' Oral presentation. Pennine Care NHS Trust Master Class. 28th November 2012. Manchester.